

# The Impact of Day Care Services on Older People with Long Term Conditions

## An Exploratory Mixed Methods Study

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## Dedication

It seems apt that the writing of this thesis took place amidst the centenary celebrations of the women's vote in the UK. I'd like to dedicate this work to Agnes Harvey, born in 1914 in the shadow of what is now the University of Liverpool's Waterhouse building. Her relationship to the building took place during its former role as an infirmary (pre NHS), being called out of school to deliver food to her mother as yet another brother was born. She possessed a sharp mind, with a skill for political debate and argument. An artful storyteller with a strong dedication to family and friends and a fierce resolve amidst hardship.

Our opportunities couldn't have been more different. During high school exams, she pointedly reminded me that at the same age she was carrying buckets of melted toffee, across a plank of wood between two buildings six floors high for ten hours per day. Thus, any claims of tiredness I had were obviously mocked. She laid the strong stable foundations of our family and was supportive of our achievements whatever they may be. She has not been far from my thoughts whilst undertaking this work, therefore I would like to dedicate this thesis to Agnes Harvey, 1914-2004.

Nan, for you. All my love and thanks, Cath x

# **Abstract**

## **Background**

Day care services support older people with multiple long term conditions (LTC) within the community to age in place. This salient topic is given little attention by researchers. Day care services models are complex and outcomes for service users unknown. In the UK, in response to wider policy reforms local authority models have been outsourced to a range of organisations, including Charitable and Voluntary services. This thesis aims to understand the models of day care provided in the community and the subsequent outcomes for users and their families.

## **Methods**

This is an exploratory study comparing outcomes for users across five different service types: firstly comparing day care provided by Paid staff services, Voluntary services and Blended services (provided by staff and volunteers) and secondly comparing services provided in urban and rural areas, with a particular focus on health inequalities. Mixed Methodology was used. Observations using focussed ethnography and semi structured qualitative interviews with staff and volunteers provided a greater understanding of the type of provision. Quantitative measures were used at 3 time points over 12 weeks of attendance with clients new to day care to assess outcomes using tools for health status and loneliness.

## **Findings**

Data was collected from nine day care centres across seven services. 94 clients and 16 carers attending day care were recruited. 36 semi structured interviews were undertaken with clients, carers, staff and volunteers at the services. At baseline there were no differences across services types in the numbers of long term conditions reported by service types but there were significant differences between rural and urban services (rural mean LTC 5.2, urban mean LTC 4.2,  $p=0.04$ ). A larger proportion of clients attending Blended and volunteer led services reported a reduction in loneliness. When adjusted for other baseline variables in logistic regression model, likelihood of reduction in loneliness was increased in Blended ( $OR=2.28$ ) and Voluntary ( $OR=2.16$ ) services compared to Paid staff service. People using Blended and Voluntary services reported better or same health outcomes across most EQ5D3L domains than Paid services. Observations and interview data suggests that the differences in outcomes at Blended and Voluntary services may be due to the delivery of activities promoting self-worth and facilitating links to the wider community.

## **Conclusion**

This thesis concludes that day care provides vital support for frail older people living at home and their volunteers can deliver effective support with favourable outcomes. It is suggested that activities that promote self-worth and provide links to the community may facilitate positive health outcomes and reduce loneliness. Preparation of such activities can be implemented with minimum resources, providing cost effective interventions for providers to deliver.

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# **1. Introduction**

## **1.1 Aging with multiple long term conditions.**

Demographic changes within society attributed to the increasingly older population are cited frequently by policy makers and the media. Common topics of debate range from: how to manage the financial and operational pressures on health services; what strategies work best to support older people living within the community and who should shoulder the responsibility of care, family or state? In this context the high prevalence of multiple long term conditions (LTCs) within this population group can be overlooked due to societal assumptions of the aging process. The majority of people over the age of 65 have more than one LTC and whilst figures such as this are widely distributed, health systems are still designed as diagnostic and curative solutions associated with acute conditions.

The impact of illness on an individual has been documented in the literature through the work of Arthur Frank (1995) referring to biographical disruption that illness creates for a patient. In contrast to the of acute illness focus within Frank's work, the contribution of Kathy Charmaz (1997) has a LTC focus discussing the changing identity of an individual. The comparison of experiences of people living with different diagnoses suggests differences in the illness trajectory between chronic and acute conditions. For older people living with frailty there is often no one event identified at the start of the experience but more an association with loss or functional decline followed by a period of adaptation and normalising (Kendall et al, 2015).

The normalisation and adaptation process, common in older age blurs the boundaries of LTCs within the aging process. This project explores the role that day care provides to older people with multiple LTCs focusing particularly on the comparison of outcomes drawing on the configuration of services.

## **1.2 The role of day care service for older people**

Day services provide support for older people living in the community with the aim of promoting independence and autonomy for those who don't require full care in a residential setting but do need regular support to continue to live independently (Clark, 2001). There is a paucity of research about day care services. Little is known about outcomes for the people that use the services. Day care is often referred to in the literature in association with the respite function it provides for carers of older people as opposed to the impact attendance may have on older people themselves.

As the aging population increases day care provides older people the opportunity to leave their homes, to interact with other people, partake in activities, receive a prepared meal and in some cases receive personal care. In the past research has reported that traditional local authority provided day care has the potential to slow down an individual's need for long term institutional care (nursing home), at a reduced cost. Changes to UK policy, reduced budgets and the introduction of new legislation means that how day care is provided, funded and accessed has changed. The role of Charitable and Voluntary services is increasing within the community but little is known about outcomes within this environment.

In rural areas it is acknowledged that the older population is increasing at a faster rate than in other areas. This provides challenges to service providers



in rural areas in terms of how to target resources and the logistics of doing so. A gap in current research is an understanding of the configuration of day care provision and its impact on outcomes for the clients attending.

### **1.3 The challenge for research**

A main challenge for research on a topic that has received little attention to date is where to start. With so many unknowns an exploratory study can open up key issues and initiate a debate around central themes. However, in terms of recruiting into studies, the day care environment is not research active so any recruitment strategy needs to be considered carefully during the project design. With day care services operating during a period of financial uncertainty, a risk to any studies would be resources in terms of time taken to establish a study with services that may relocate, change provider or cease to exist during the lifetime of the project.

The population group using day care is described in the literature interchangeably as a hard to reach or vulnerable group. For many studies working with older people the carer may be the focus providing the perspective on behalf of the older person. An additional challenge for studies is the prevalence of illness and periods of poor health due to their LTCs. Changes in social situations due to bereavement or relocation to be close to family may also cause issues for any follow up aspects of outcome-based studies. The accessibility of tools for people with LTCs need to be planned carefully so that sensory, physical or communication difficulty can be accommodated appropriately.

## **1.4 Thesis Structure**

This thesis is presented in the following nine chapters with the early chapters dedicated to the preliminary work of the study. Chapter two provides the background to the thesis addressing concepts key to the topic, discussing wider policy surrounding the provision of day care, leading to the conceptual framework used to develop and design the study. In chapter three the evidence in the literature is explored by way of the systematic review. Chapter four describing the approach taken by liaising with day care providers and users, when designing the study. This process is often overlooked in academic work where publishable work is regarded as a priority despite goal collaboration considered to have research impact (Irving and English 2008).

The evidence revealed in the systematic review and situated knowledge from those familiar with day care provision, were combined to define the aims and objectives for the study presented in chapter four. Chapter five outlines the methodology and selected data collection tools of inquiry and analysis with a further section identifying issues encountered with regards to the application of the methods within the day care setting. The thesis acknowledges the complexity of service design within the day care setting and the choice of more than one method chosen from perspectives gives a depth to findings. Nine centres were selected for their type of service and geographical area. All services could be recognised as day care with similar attributes however, exact equivalency of settings was not sought therefore the choice of methodology enabled a wider understanding of diversity in service provision.

For the purpose of this thesis the day care services taking part in the study were selected in order to recruit participants from both urban and rural areas.

In addition, services were categorised into three types of provision dependent on the workforce providing day care for older people. Paid services were managed and operated using paid staff who were employed directly within the organisation to provide the service. Blended services were managed by paid staff and whilst supported by volunteers the service was coordinated by a paid member of staff. Voluntary services were managed and operated by volunteers

The findings of the study are presented from chapter six through to nine, with the data reported from three perspectives (services, client and carers). The order in which findings are presented does not indicate any additional weighting given to the perspective from the service. It is merely to provide context for the reader to understand how the service is delivered before moving onto the perspective of the clients. Chapter six describes evidence regarding service provision. Chapter seven provides the findings from quantitative work that obtained data relating to outcomes from clients new to day care and at two follow up intervals. Chapter eight presents findings from qualitative work undertaken with clients after 12 weeks attendance at day care and chapter nine presents evidence from carers' perspectives.

The challenge of mixed methods utilising multiple data sources is that findings may become unwieldy and difficult to manage. Triangulation enables the results of one method to be cross-checked with another (Bryman, 2004). Therefore following the presentation of evidence, chapter ten then commences by highlighting associated findings between data sources. The chapter then proceeds with the findings of the study presented according to each objective. The thesis highlights study strengths and limitations, with

implications for research, practice and policy makers discussed before conclusions draw the thesis to a close.

## **2 Background**

### **2.1 Introduction**

This chapter outlines the background to the thesis. It commences by defining day care services for the purpose of this study and alluding to the complex and diverse nature of services. Day care aims to support older people to age in place in their own home, in their own community. It is a preventative service aiming to delay decline and the need for long term care, whilst simultaneously serving as a respite service for carers.

The function of day care to support older people means that it is important to understand the concepts of aging and the debates regarding the increasing aging population. On the one hand there are positive concepts of aging well, with healthy longevity the attainable goal. On the other hand there are the negative associations of aging, such as loss of relationships, health and mobility. The prevalence of (multiple) LTCs in this population group provides the backdrop of one of the key policy issues in the current debate, service utilisation. The changing aging demographic brings challenges for services not just in terms of the types of interventions but how they can be delivered. As the aging population increases faster in rural areas, the configuration of services in this environment need to be properly considered.

The chapter continues by highlighting key terms often used when discussing the aging population such as quality of life, independence, wellbeing, loneliness and social isolation. Central to the discussion around the support older people with long terms conditions require is where the responsibility should lie. Is it the role of the family (if applicable) or for the state to address

via legislation and policy? The wider policy objectives outlined, illustrate the desire to provide choice and individualisation through services. However key strategies involve addressing high intensity service use by older people with health and care needs.

Care policy is implemented against a backdrop of austerity associated budget cuts. In response the provision of day care is evolving to accommodate different funding streams, reduced budgets, new referral pathways and accessibility criteria. Services are under pressure to demonstrate positive outcomes for people using their service. However, little is known about outcomes for people using day care services.

The final part of the chapter outlines the conceptual framework for the study, using the lens of health inequalities generally and more specifically in relation to research. It explains the research standpoint and theoretical basis for the thesis, setting the scene for the systematic review of the literature.

## **2.2 What is Day Care?**

In the UK, Day Care services are provided for two population groups; Adults with disabilities and Older People. The definition by Tester (2001) is used for the purpose of this project:

*“A day care service offers communal care, with Paid or Voluntary care givers present in a setting outside the user’s own home. Individuals come or are brought to use the services which are available for at least 4 hours during the day and return home on the same day”.* Page 37.

In addition to this the length of attendance of four hours requires that food provision is provided whilst at the centre. A challenge of a project set within

day care is the range of provision and ultimately defining day care. Looking beyond the UK in the international literature, the definition in the US for Adult Day Care Services is a wider definition:

“Adult day care services support the social, health, nutritional and daily living needs of adults in congregate settings during daytime hours”.  
(Anderson et al, 2012, p1).

A challenge of a project set within day care is the range of provision and ultimately defining day care. The reference within the US definition to daily living needs portrays a wider definition of day care and whilst some services in the UK do support aspects of personal care it is not commonly available in all centres. Another service in the UK that can be confused with day care is the day hospital. Day hospitals tend to be funded through the NHS and focus on the maintenance of skills and rehabilitation following periods of illness. Patients would utilise this service over a short term period at the end of which a new rotation of patients would commence their time with the service. In contrast, day care is usually under the domain of social care (non medical) with day centres providing respite for carers and maintaining levels of independence (Powell & Roberts, 2002). Clients at day care can stay with the service for much longer periods of time, in many case years.

Prior to describing the current policy context for day care services in section 2.4, it would be useful to understand the concepts pertinent to the users accessing day care support.

## **2.3 Aging**

In the UK the number of people aged over 65 is the fastest growing age group. In 2006, 18% of people in the UK were over the age of 65 and 2.4% over the age of 85 (ONS, 2017a). The over 65 age group is expected to rise to make up 20% of the population by 2024 (ONS, 2016). Across Europe, the oldest old (over 85 years) population is projected to increase from 5.4% of the population in 2016 to 12.7% by 2080 (Eurostat, October 2017b). To put this into context, internationally by 2030 the number of people in the world aged 60 and above is expected to increase by 56% (UN, 2015).

In the UK the life expectancy gap between men and women is closing, due to a fall in the proportion of males who smoke and hold high-risk occupations (ONS, 2017). This shifting demographic of an increasing aging population has been described as a national concern (Lamb, 2014) and is frequently referred to by the media and policy makers. It is for this reason the concept of aging will be discussed in more detail below.

### **2.3.1 Successful Aging**

How the aging process is viewed as part of the life course can be integral for services in terms of how they support older people that use them. The phrase successful aging was used initially to counter ageist assumptions, considered negative and detrimental, assuming a decline in function and contribution during the period of old age (Lamb, 2014). The model conceptualised by Kahn and Rowe (1997), places control of the aging process with the individual rather than a natural process that one should resign oneself to:



“aging is dependent on individual choice and behavior. It can be attained through the individual choice and effort. Also continue to live in one’s own home, taking care of oneself”. (Rowe and Kahn, 1997)

Conceptualising aging in this way relies on the biomedical model of health in terms of the absence of disease and disability. It has been referred to as the third age (Gilleard & Higgs, 2005). It stresses that life changes are not necessarily negative but are a normal part of the aging experience where decreased psychological wellbeing is not a given (Pearlin and Skaff, 1996). With this in mind it has been stated that the dominant discourse has the objective of eliminating the category of old age. However in response to this Kahn has clarified that the concept of successful aging “means aging well which is very different from not aging at all” (Rowe and Kahn, 1998 p49).

However, criticism is levelled at the choice aspect of this model as it creates a dichotomy between those who can “choose” and those who are unable to choose then becoming marginalised (O’Dwyer, 2013). It has been highlighted that this concept of aging over emphasises independence rather than acknowledging long periods of interdependence that can be common in older age, creating separations between what has been referred to as the “well-derly and ill-derly” (Moody, 2009 p68).

It is stated that the over emphasis of positive aspects of aging in the realms of biomedicine promotes stigma for those experiencing frailty and dependence regarded as failure (Lamb, 2014). The dominant discourse of aging well means that there is a lack of studies that explore the in between state that an individual experiences when they are in transition from independence to

interdependence (Leibing, Guberman and Wiles, 2016). This leads us to the association of aging and loss.

### **2.3.2 Aging and Loss**

The assumption that aging is a period of decline accompanied by illness and disease affects older people's engagement with services and the wider community. For example older women report that aging conceals symptoms of chronic illness with patients viewing symptoms as merely part of the aging process (Roy and Giddens, 2012). It has been stated that whilst conversations have been encouraged around taking control of decisions at the end of one's life, this has not been matched by promoting conversations around losses that are common in the aging process or as part of the natural flow of life (West and Glynn, 2016). Therefore, as discussed above, the avoidance of unwanted conditions are promoted for as long as possible (Laslett 1989) with increased anxiety common around prospective physical and mental decline (Layton, 2009). The third age is promoted with positivity and control and the fourth age becomes invisible or marginalised. In response to the successful aging model above, a model of conscious aging is proposed that expands the notion of aging successfully to include the recognition and adaptation of decline rather than attempts to postpone this (Moody, 2009).

### **2.3.3 Long Term Conditions**

Long term conditions (LTCs) are conditions for which there is no cure, are life long and require ongoing drugs or treatment to be managed (Goodwin et al, 2010). Long term conditions are also referred to as chronic conditions. In the UK, LTCs are the leading cause of ill health and disability, disproportionately common amongst socially deprived groups (Blickem et al, 2013).

Acute conditions are severe in their onset and alleviated, treated or cured by medical intervention. Historically, health systems have been organised around this concept. In contrast LTCs develop over time, with exacerbations occurring intermittently. Charmaz draws on this component of living with a long term or chronic condition (Charmaz 1997) suggesting that the unpredictability of a chronic illness disrupts the daily life so patients move between good days that bring hope but then bad days which dash it again. Due to the dominance of the acute illness model in western culture, illness is perceived as an interruption from which people should recover. However, the impact on the individual's functioning is less predictable as the sketch in figure 1, illustrates. The drawing was made by a person with a LTC, during a workshop to illustrate their day to day experience (Royal College of General Practitioners, 2011).

The red line highlights the episodic consultations the person living with a LTC needs to manage their condition. The wavy line represents the experiences of their symptomatic peaks and troughs. In the UK, people with LTCs received focus from the government in the creation of a national strategic framework outlining standards expected to enable them to live as independently as possible (DH, 2005). However, the LTCs referred to were neurological only. LTCs are further reaching than this and can include mental or physical health or both. Taylor et al (2014) produced a list of 77 LTCs illustrating the breadth of the types of conditions applicable to the thesis.

There have been calls for more empirical work to understand the barriers and enablers for people accessing support (Blickem, 2013). However, there is a tendency for researchers to focus on particular conditions such as stroke,

dementia, or diabetes and not explore LTCs as an overall concept. The emphasis of LTCs that may cause visible or identifiable disability was challenged in the UK by the Care Quality Commission. It was established that people with invisible conditions such as mental health conditions were less likely to report positive experiences of using services, culminating in the Invisible Conditions Campaign (CQC, 2016). The concept of invisible conditions is pertinent to the population of older people, especially when considering that the aging process can conceal the symptoms of chronic illness (Roy and Giddens, 2012) as reported in section 2.3.2.

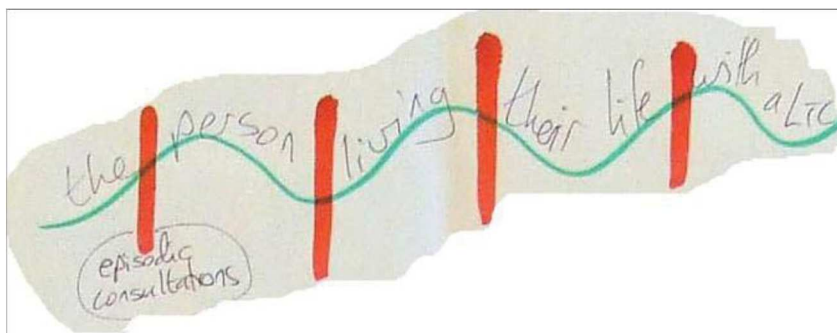
There is evidence that the number of LTCs a person has can be a greater determinant of their health service utilisation than specific singular conditions (NHS, 2014a). An understanding of multi morbidity is provided in section 2.3.4

#### **2.3.4 Multimorbidity**

Multi morbidity is defined as more than one chronic condition (van de Akker, 1996). They are responsible for major disability and death due to losses in hearing, seeing and moving plus non-communicable diseases such as heart disease, stroke and chronic respiratory disorders, cancer and dementia (WHO, 2015).

Multi morbidity is associated with higher healthcare costs (Maregoni et al, 2011). In Europe 34% of people over 65 years of age use 5 or more prescription medications (Junius–Walker et al 2007). Multiple medications may increase the risk of problems associated with aging such as cognitive impairments and falls (Hajjar et al 2007).

Figure 1: living with long term conditions – a patient's perspective



Individuals with multi morbidities are more likely to die prematurely (Poses 1996) and stay in hospital longer (Librero, 1999 and Rochon, 1996). It is reported that unplanned admissions are exacerbated by the co-existence of mental health conditions and socio-economic deprivation (Payne et al, 2013). Despite this the strategic focus of healthcare in the UK in the form of National Strategic Frameworks (NSF) is still on single chronic conditions (Lewis, 2004) for example, cancer, diabetes, heart disease. Systems are designed around a single disease approach (Barnett et al 2012) providing challenges to those with multimorbidities arising from LTCs accessing services appropriately. It is recognised that self-management enables people to maintain control of their own lives and their own condition. There is a lack of research into interventions that improve outcomes for people with multiple morbidity with focus to date only on exploring comorbid conditions. Therefore the importance of improving outcomes for people affected should be recognised (Smith et al 2012).

At this stage it can be seen why the third age concept aims to negate the associations with decline. The prevalence of LTCs in this age group and discussions around policy could stereotype old age from the biomedical point of view. As day care aims to reduce acute service use or long term care, the next section will discuss the association of older people with LTCs and their utilisation of other services.

### **2.3.5 Older People and Service Use**

Data from the Department of Health shows that although people aged 75 or older represent around 8% of the population, they nevertheless account for around 28% of NHS expenditure (Department of Health, 2013). Over the last decade hospital emergency readmissions has increased, with a sharper

increase in the over 75s (Age UK, 2013). Most people with LTCs have two or more conditions (Gray and Leyland, 2013). There is a group of people with high impact multi morbidity who are difficult to manage, leading to repeat attendance and use of health services (Foster, 2006).

During a time of crisis, patients and professionals alike default to hospital (Thwaites et al, 2017). Carers of older people self refer to emergency services in hospitals to access packages of care when levels of care and support are not enough. There is growing evidence that at around the age of 70, spending falls significantly and expenditure outside traditional health systems increase (Oliver, 2014). However the type of support available is a topic of debate within society in terms of what could or should be provided. On a basic level, there is support to assist people wash and eat, preventing admission in to longterm care. At the other extreme is the concept of supporting people so that they can be active participants in society (Close, 2017). Day services have a role to play in this climate as they are viewed as promoting independence and autonomy for older people who do not require full care in a residential setting but do need regular support to continue living independently (Clark, 2001).

The configuration of the aging demographic also brings challenges logistically as the next section will discuss, in terms of aging in rural areas.

#### **2.3.6 Older People in Rural Communities**

The elderly population is increasing at a faster rate in rural areas than in urban areas, with differences in the age range of the population causing difficulties in service provision. This is due to a lack of younger families in rural areas, resulting in volunteer shortages and lack of local care staff (DEFRA, 2013). It is predicted that those over 65 years of age will make up 29% of the population,

an increase of 20% increase by 2021 (esrc.ac.uk) Nearly half of all volunteers offer their services in the community care setting, in particular day care and social support, while the types of roles undertaken differ between rural and urban areas (Hussein and Manthorpe, 2012). The service provided by volunteers in these areas is of particular value to people who rely heavily on services such as people with multiple LTCs (Gray and Leyland, 2013). The logistics of accessing day care in rural areas impacts on the number of hours that care can be provided and barriers to regular attendance are exacerbated here (Joseph Rowntree Foundation, 1995).

The key issues in rural areas are housing, health and transport. Older rural users tend to rely on private transport whilst individuals still possess a driving licence. However a loss of driving licence reduces social and civic participation. It has been suggested that service providers could design services in a more strategic and proactive way rather than reactively to reduce expense (Holley-Moore and Creighton, 2015).

Recent austerity cuts to funding have affected more rural areas the most due to their higher proportion of retired residents (Commission for rural communities, 2012). Isolation has been compounded in rural areas due to fewer community facilities combined with inaccessible, poor quality and expensive transport. There are higher levels of loneliness in rural areas compared with urban areas, highlighting a need to focus on the needs of older people in these areas.

### **2.3.7 Quality of Life**

Continuing with the topic of debate in terms of how much support older people should be entitled to, a number of key terms are voiced interchangeably such



as quality of life, independence and wellbeing. This thesis uses the definition provided by the World Health Organisation below:

“The individual perception of their position in life in the context of culture and value system in which their lives and in relationship to their goals expectations and standards” WHO 1996

The definition above places the concept of quality of life as viewed by the individual themselves. Here their goals expectations and standards will define their needs and requirements from services. Therefore, the importance of viewing older adults as a diverse group with a range of needs and interests rather than a homogenous group (Pardasani et al, 2009) is emphasised at this point and will be discussed later in the thesis.

It has been reported that the drivers to promote the quality of life for older people can be categorised into themes of psychological, health, social and neighbourhood (Bowling, 2011). The psychological theme refers to an individual's expectations; health constitutes mobility and physical functioning; social refers to participation and support and neighbourhood refers to social capital or access to facilities and sense of security found within ones local area. The individual's subjective view of their quality of life is affected by whether they feel they have adequate income to be able to retain control over their life, which leads us onto the notion of independence.

### **2.3.8 Independence**

The term Independence is used interchangeably in policy associated with quality of life. It is useful therefore at this point to describe the concept as it is defined for this project. Three concepts of independence, mobility and

wellbeing are closely interlinked (Schwanen & Ziegler, 2011). Functional capacity or mobility is often highlighted within the definition of independence, as the example below illustrates:

“Independence is most frequently associated with an individual’s level of functioning and ability to form the activities of daily living unaided”  
(Davies, Laker and Ellis, 1997 p409)

However, another example relies less on physical functioning, as the UK government suggests that the main threat to older people’s independence would be the loss of their ability to exercise control and choice over their daily living (Parry et al, 2004). This notion is more closely assimilated with the definition from Leece and Peace (2010) that suggests that there are two components of independence: decisional autonomy being the ability and freedom to make decisions and executorial autonomy being the ability and freedom to carry out and implement personal choice. Therefore for the purpose of this thesis the Leece and Peace definition will be considered, rather than a definition more aligned with ableist society in which physical functioning is central to engagement and access to wider society. Therefore, by supporting or promoting independence with or without physical functioning enables older people to remain engaged in society.

### **2.3.9 Wellbeing**

As mentioned previously, wellbeing is a term that is often used interchangeably with quality of life and independence. Wellbeing is perceived to be wider than independence and refers to broader psychological and physical resources and social connections. Components central to quality of life are also integral to concepts of wellbeing (Leece and Peace, 2010). For

example, relationships with others and a role within society are a common theme of the two definitions. Historically within the literature, quality of life was perceived to be a subjective measure for individuals and wellbeing an objective measure (Langlois and Anderson, 2002).

This thesis draws on the more contemporary definition of wellbeing in its general terms of good health and positive social relationships (Centre for Disease Control and Prevention, 2016). This leads onto two concepts pertaining to the nature of social relationships: Loneliness and Social Isolation.

#### **2.3.10 Loneliness**

For the purpose of this thesis, loneliness is considered to be a mismatch between the quantity and quality of a person's relationship's and their desire or expectations for relationships (Peplau and Perlman, 1982). It is recognised that not all individuals seek numerous social relationships therefore it is this gap between the number of relationships that an individual perceives to be sufficient and the number of relationships that they actually have. The presence of loneliness is therefore subjective and personal to the individual. Weiss (1973) suggested that loneliness has social and emotional dimensions. Social loneliness refers to the absence of an acceptable social network that provide belonging and companionship. Emotional loneliness refers to the absence of attachment figure or someone to turn to.

Despite loneliness being a fluid or intermittent experience, 5-16% of people aged 65 and above report feeling lonely all or most of the time (Goodman, et al 2015). There is evidence that loneliness can be a consequence of poor health whilst also causing negative health outcomes. It is agreed that

loneliness can have a negative impact on people's quality of life, mental health and physical health (De Jong Giervald et al, 2006, Greene, 1992). Individuals who experience loneliness may be socially isolated and the two terms are often used interchangeably. However, an individual may have a number of social connections but still have that mismatch for intimate social relationships that mean that levels of loneliness still exist. This will be discussed further in the next section.

#### **2.3.11 Social Isolation**

As discussed above, social Isolation is different to loneliness. Loneliness is a subjective state, whilst social isolation is an objective state regarding the lack of meaningful and sustained communication (Poscia et al, 2018) and frequency of social contact. Older adults that maintain social networks have fewer depressive symptoms (Oxman,1992). Social connections are beneficial for psychological and emotional wellbeing and physical health (Uchino, 2006). The causes of loneliness can be attributed to societal and individual factors. In the wider community factors are reported to relate to transport, the physical environment, the community, housing, technology, level of crime, and population changes. On a personal level factors include, poor health, sensory loss, loss of mobility, less income, bereavement, retirement and requiring care, risk factors that all increase with age. (ADASS, 2014, Tester 1996).

#### **2.3.12 Role of the Family**

In addition to the societal debate about what level of support older people should be entitled to, there is an additional debate ongoing regarding the role of the state, individual and families in the provision of support. Unpaid carers, usually family and neighbours currently provide support within the community

saving £2.5 billion per week costs to the government (Carers, 2015). However, the UK government feels society needs to do more and the UK needs a societal change. Internationally, there are other countries that have legislated to promote intergenerational support for older people. For example, India introduced a maintenance and welfare of parents and senior citizen bill in 2007 which promotes the family as key to elder care as opposed to self reliance or support from the state. Another example in China is the elderly rights law that states that children have to visit their parents although it fails to provide a frequency more specific than “often” (Lamb, 2014).

In response to the vision of the UK government there are concerns about people who do not have family. It is estimated that a gap in the number of families able to provide care will grow further. The number of older people needing care is expected to outstrip the number of adult children available to provide care for the first time in 2017. This emphasis on the role of families could further stigmatise older people transitioning into the fourth age of dependency who are doing so without family.

For those older people that do have children, it is reported that there is a fear of dependence on their children or other relatives, regarding it as demeaning (Lamb, 2014). In order for older people to accept support from family, a reciprocal arrangement is usually the favourable option (Bowling, 2011).

## **2.4 Wider Policy**

As the previous section has described the concepts associated with the people utilising day care services, it is now possible to discuss the implications and relevance of current policy within the UK.

### **2.4.1 Policy and Aging**

A common theme for services is the recognition of the potential to prevent or delay older people from deterioration in their physical and mental wellbeing. The concepts central to the third age discussed in section 2.3.1, are representative of the policies implemented in response to demographic changes (Barnes, Taylor and Ward 2013). NICE guidelines published for older people in recent years, include the following topics: recommendations for independence and wellbeing (2015), independence and wellbeing for people with dementia (2013), falls in older people (2013), home care for older people (2016) and social care for older people with multiple LTCs (2016). The reduction on public sector reliance by older people is an aspiration of the joint commissioning process between health and social care services (Allen et al, 2013).

It has been suggested that old age is no longer just a stage in the life course but a problem for policy makers to contend with (McDonald and Mair, 2010). In the health service, unplanned hospital admissions receive ever-growing attention. Health and social care costs increase in relation to multiple LTCs with emergency services experiencing the greatest increase (NHS England, 2014a). People aged over 65 years of age have the highest risk of falling with an estimated cost to the NHS of more than £2.3 billion per year (NICE, 2013). One response from services is to prevent the further loss of mobility and maintenance of independence. Services that can delay a reduction in mobility and physical functioning such as re-ablement services have received increased attention in view of the increasing aging demographic (Kjerstad and Tuntland, 2016).

There has also been an increase in focus on older people who are admitted to hospital. 62% of hospital bed days were occupied by older people age 65 years and over in 2014/15 with an estimated £820 million cost to the NHS due to older people using hospital beds with no need for acute treatment. There was a 31% increase in delayed transfer from acute hospitals between 2013 and 2015, with the need for a home care package or nursing home placement the most common trigger (NAO, 2016). The attention of such policies and figures risk categorising older people as merely dependents, recipients requiring care and support. However, legislation such as personal budgets aims to give people more choice and control over the care they receive (House of Commons, 2016).

Choice and control as an objective of legislation such as personal budgets and wider policies is referred to as the personalisation agenda (Leadbetter, 2004). This describes a way of working that respects the uniqueness of individuals and tailors services to the individual (Henwood & Hudson, 2008). It links to the WHO definition of quality of life referred to in section 2.3.7 whereby the individual's goals, expectations and standards are put at the forefront of policies. Legislation such as the Caring for our future 2012, (UK Government, 2012), encourages further outsourcing of services to the private, independent and Charitable services. Considering this, the role that non- statutory non-health organisations play in the community should be considered when addressing the response from policy makers. Poorer households and communities who are multiply disadvantaged are most significantly dependent on access to a full range of public services and welfare benefits to improve opportunities and sustainable solutions (Hirsch, 2004). It has previously been

suggested that health work should be reconceptualised as an activity that takes place outside of the clinical settings (Wanless, 2004).

The societal debate regarding the responsibility for social care and supporting older people was alluded to in section 2.3.12, Role of the Family. There is recognition that improvements need to be made in terms of the extent of provision, accessibility and integration (CQC, 2010) but as of yet improvements are yet to be made. The agreement on the types of policies the situation requires is one step towards resolving the issue. How the cost is managed, whether it be through the state or responsibility of the individual is yet to be agreed. Funding issues are tied to a wider programme of austerity, discussed in the next section.

#### **2.4.2. Austerity**

The term austerity tends to be used to denote budget cuts however the aim of austerity policies is to restore government finances by cutting levels of consumption such as pensions, health and education (Schui 2014). Local authorities currently face a high share of the spending cuts (Hastings et al, 2012). Adult social care funding has reduced 17% since 2009/10 (Quilter-Pinner and Snelling, 2017). In order to balance the books many local authorities have increased user fees and co-payments for care services with a 12.5% increase nationally between 2008/09 – 2012/13 (Yeandle, 2016).

Community services for older people, such as home care and day care have seen the biggest reductions in local authority spending, 23% between 2009/10 and 2012/13 (Ismail et al, 2014). By increasing the threshold for eligibility for



social care it is reported that by 2011, 78% Councils had stopped supporting people with 'Low' or 'Moderate' needs. (Duffy 2013). Local data is limited regarding the impact of this but the existing evidence base shows significant growth in older people self-funding the services they require and predicts significant future unmet need (Burchardt, Obolenskaya, & Vizard, 2015).

In response to this, volunteer-based schemes, some constituted as "social enterprises," delivered primarily by older people themselves, expanded and provided support to more older residents than were receiving home care and day care support (Yeandle, 2016). There is a lack of evidence as to how efficient volunteer delivered services are (Cattan, 2011). New comparative studies examine how support is redesigned, and its longer term impact on older people, carers, and service providers are needed (Yeandle, 2016).

The next section will discuss the relevance of wider policy and austerity specifically in relation to the provision and accessibility of day care services for older people.

#### **2.4.3 Evolving Day Care Services and Current Policy**

Following the introduction of multiple policy initiatives mentioned in section 2.4.1, such as personal budgets and the 2014 Care Act, the wider government austerity policy has seen local authority spending reduced. In the last decade the number of local authorities that still consider people with moderate needs to be eligible for funding has reduced, with the Charitable and Voluntary sector in many areas providing day centre services in the absence of local authority provision. Caring for our future, White Paper (HM Government, 2012) enables local authorities to relinquish the delivery of adult day care and encouraged

the future delivery of former local authority services to be provided by a combination of private, public and Voluntary sector organisations.

The introduction of the Care Act 2014 (UK Government, 2014) replaced the previous assessment criteria for people requiring care as support needs classed as mild, moderate, substantial and critical, with a national minimum threshold that individuals must meet in order for local authority to fund or provide services. Although this is expected to be equivalent of the previous substantial level of assessment, there is concern that intervention should take place earlier to reduce or delay the need for support later (McNicoll, 2014). Faced with reducing funding levels, local authorities are having to restrict funded social care to individuals with more pressing needs instead of being able to fund preventative work (Commission for rural communities, 2012). Charities supporting adults and carers which focus on the higher threshold of need believe those with moderate or lower needs are vulnerable and lack support to remain independent and active (Age UK, 2014).

Therefore the climate day care is operating in differs from the recommendation put forward in section 2.4.1 in terms of a community preventative model. As the environment that day care operates in shifts, it is useful to note the function of day care and the role it plays in wider support for older people within the community. As mentioned above day care service models are mixed and involve complex arrangements (Gridley 2012). In order for co-ordination to be good it is expected that development of services will be time demanding, resource intensive and yet at risk of being undermined by local authority funding (Bamber et al, 2012 in Henwood & Hudson, 2008).

More recently providers are commissioned to provide deliverable outcomes for users at the service. The next section gives an introduction to outcome-based commissioning then moves on to what this means for day care services in section 2.4.5.

#### **2.4.4 Outcome based commissioning**

Commissioning for outcomes calls for an increased focus on the results achieved by services interventions and calls for more accountability in commissioning and the creation of financial incentives. (NHS England, 2014b). Providers are tasked with finding better ways of delivering services. However there can be confusion between individual outcomes and system level outcomes (Hoong Sin, 2016). The Berlin declaration on the quality of life for older adults highlighted the need for more studies to examine the type of interventions that were optimal in particular parts of the life span and subsequent implementation (Fernandez-Ballesteros et al 2009). This provides an example of the relationship between individual and system level outcomes in the commissioning environment.

It is reported that there are current gaps in understanding which preventative services work best in different contexts and this is likely to continue (Allen et al 2013). Although during times of austerity and reduced budgets, it would be expected that impact measurement would be utilised, it is suggested that this is not usually undertaken in any depth in the third sector (Ogain et al 2012). The following section will look at outcomes as they relate to the day care environment.

#### **2.4.5 Day Care Outcomes**

In terms of outcomes within day care, there is a lack of robust evidence to substantiate whether day care improves quality of life for patients with chronic long term and life- limiting conditions, and their caregivers. Little is known about different models of day care and their impact on the patient experience and whether some may have greater benefit and therefore be more appropriate for the future needs of people with LTCs. Day care provides respite for carers but there is little understanding relating to the prospective enhancement for the person attending day care. Negative connotations suggest it may merely provide a containment function to keep older people safe and reasonably occupied while their carers are at work (Age UK, 2011).

As discussed in the introduction to this chapter, Fields et al (2014) in an international systematic review, found the effectiveness of day care was difficult to assess due to the lack of a standardised definition. This lack of a strong conceptual model within adult day services means that there is a difficulty connecting participant needs and services to specific outcomes. This causes difficulty in understanding what works, for whom and in what circumstances within the day care setting (Dabelko and Zimmerman, 2008).

Chapter 3 provides the findings from the systematic review of the research literature undertaken as part of this project, whilst chapter 4 provides the understanding of day care services currently operating on the front line in the UK. First however, the next section will discuss the standpoint of the research project and theoretical framework guiding the study.

## **2.5 Conceptual Framework**

As discussed in the introduction, the study was funded by CLAHRC, NWC (Collaboration for Leadership in Applied Health Research and Care, North West Coast, 2018), with its overarching theme of health inequalities and this guided the research in terms of its focus and design. The section discusses the various frameworks employed within the study.

### **2.5.1 Health Inequalities**

This section will initially describe what is meant by the term health inequalities and then go on to discuss their importance in relation to the study.

Health Inequalities is the term used to explain that there are systematic differences in the health of people who occupy unequal positions in society (Graham, 2009). The association between socio-economic status and prevalence of individual chronic disease is well established (Marmot, 2010) however there are few studies that focus on the connection between multimorbidity and socio-economic status and little is known about the relationship between social economic status and mortality (Lund, 2017). When looking at different local authority areas, rather than observing merely differences in health status, there are clear significant variations across local authorities demonstrating health inequalities.

This is not a new concept. In the UK the Black Report (Black, 1980) demonstrated that ill health and death was unequally distributed across the UK and that health inequality was attributable to wider social inequalities in housing, income, diet, education and employment. More recently the Marmot Review (Marmot et al, 2010) drew attention to the prevailing social determinants of health in terms of how the conditions where people are born

and live can lead to health inequalities. For example, men and women in the most advantaged areas show a similar life expectancy at age 65, being expected to live a further 19.3 years and 20.1 years respectively. However in the most deprived areas, men have a life expectancy which is 9.2 years shorter than men in the least deprived areas; while females can expect to live 6.8 years less than females in the least deprived areas (Evandrou et al 2015). Older people from lower socio-economic background are more likely to experience poorer health outcomes compared to people from a higher socio-economic background, with education being the main indicator (Rahman et al, 2016).

There are suggestions that the reason for this is that individuals in more deprived social groups may be more reluctant to present to doctors with their symptoms (Richards et al, 2002). It is reported in numerous countries, that the better off are more likely to visit doctors and dentists and take up invitation for breast and cervical screening more, making more use of services (Devaux, 2012). To consider this in terms of LTCs, Steel et al (2014) compared the self-reported illness burden for 5 LTCs (angina, cataract, depression, diabetes and osteoarthritis) and concluded that higher illness in less wealthy participants was not matched by appropriately higher levels of diagnosis and treatment. Poverty and inequality impact on disadvantage in accessing service while low aspirations (by professionals and service users) also limit opportunities (Rosengard et al, 2007).

If we look at the role professionals or services play in health inequalities, the experience of people with dementia provides further examples. It has been reported that for people who require access to anti-dementia drugs, the least

deprived patients were 25% more likely to be prescribed anti-dementia drugs illustrating issues with access for those living in more deprived areas (Cooper et al, 2016). When focusing on people's ethnicity it was found that people from minority ethnic groups are diagnosed with dementia later in the illness, and those from Black ethnic groups are 30% less likely to receiving cholinesterase inhibitors (Cooper et al 2016). As sociodemographic factors influence risk of entry to institutional care in England and Wales (Grundy and Jithal, 2007), the example above illustrate where improvements could be made for the older population.

Socially disadvantaged elderly people perceive greater barriers to accessing healthcare services than those who are better off (Hoebel et al, 2017). Disabled people face barriers to accessing timely and effective health care including preventative interactions (Allerton & Emerson, 2012). Accessibility of health facilities, goods and services has four subdimensions: Non-discrimination, physical accessibility, economic accessibility or affordability, and the accessibility of information. Specific consideration will need to be given to the needs of older people to ensure that environments are accessible, including homes, public spaces, buildings, workplaces and transportation (WHO, 2015). Therefore the assumption can be made that infirmity is not an inevitable consequence of being old and is actually a consequence of material and social neglect in particular caused by age associated health inequalities (Gilliard and Higgs, 2010).

The term Inverse Care Law was coined by Julian Tudor-Hart (1971), to refer to this mismatch between need and supply whereby those living in deprived areas had more health problems but had shorter clinical encounters. In

addition access to care took longer and satisfaction with access was significantly lower in deprived areas (Mercer et al, 2007). To consider how health inequalities are associated with social isolation or loneliness, it is reported that people who live in deprived environment are likely to have lower levels of social participation than those who don't (Ferragina et al, 2013).

It is not just the deprived areas that service models do not meet the needs of the population. It is reported that in rural areas, current models of health and social care does not meet the needs of older people therefore in some area a tripartite model was created whereby the community became the third party to develop a "caring service" to support older people with LTCs (Jackson, 2014).

In terms of access to care another relevant issue pertaining to day care is the fact that many older men are unwilling to consult GPs and men especially from working class backgrounds less likely to access social clubs or day centres. Therefore with the increasing ratio of men in the older population (see section, 2.3), understanding the services that they would find beneficial should be evaluated.

Before the standpoint and theoretical framework are outlined in more detail, it is necessary to take a further step back regarding the concept of inequalities. The next section describes the inequalities impinging on the research agenda. This provides the basis to understand how the study design and methodology (chapters 4 and 5) were formed to combat the lack of focus on the research about day care services, alluded to in the introduction (section 2.1).

### **2.5.2 Inequalities in Research/Involving Service Users**



This section will extend the theme of health inequalities by moving one step back to consider the role that research plays in the improvement of health outcomes. This is also an environment of inequality largely attributed to the ownership of priority-setting for studies. It is reported that less research on older people takes place compared to children (McCormick et al 2009). The issues extends to the approach and methods chosen for research studies, for example a Swedish study by Kelfve (2017) investigated if estimates of health inequalities were affected by the exclusion of older people not living in the community from studies. It was concluded that absolute and relative health inequalities would be under estimated without inclusion of people living in institutions or by using a proxy interview for those living in the community.

To consider the gold standard research method of clinical trials, the issue around co-morbidity means that older people tend to be excluded entirely despite their altered physiology (Zulman et al, 2011) which in turn limits the usefulness in terms of proposed outcomes of older people (Boyd, 2012). Ultimately, the evidence base for managing chronic conditions is based on trial of interventions for single conditions with multi-morbidity excluded (Fortin 2006). It has been reported that older people are the largest group of users of services but they are the least involved in efforts to determine what has been or will be useful and effective to them (Age UK, 2014). Older people may also find themselves excluded from research due to their perceived vulnerability. The definition of vulnerable population groups in research can be ambiguous but vulnerability due to age is cited along with vulnerability due to membership of marginalised groups, disability or disadvantageous power relationships for those planning research studies (E.S.R.C, 2018). The guidelines are provided

to ensure that people are not coerced or pressured into taking part in research studies but instead risk marginalising an already hard to reach group.

The service central to this study has been overlooked by researchers with day care reported to be a neglected area, McVicker (2004). In addition there is a dearth of research into interventions to improve outcomes for multi morbidity across health and social care services (Smith et al 2012). Age UK (2011) undertook an evidence review looking at the effectiveness of day care in the UK and highlighted the paucity of research in both quantity and quality. Research undertaken in day care settings does not describe populations or the host organisations (Manthorpe, 2014), therefore creating problems to apply any findings of note into practice. A key component of this study that developed was the need to understand and report how the current service models were evolving. The disparity in the research environment, lack of focus on particular diseases or conditions and exclusion of certain population groups is of a particular interest and forms the standpoint for the research to be undertaken. This will be described in further detail in the next section.

### **2.5.3 Positionality or Standpoint**

The overarching standpoint of the researcher is one aspect of what is referred to as the researcher's lens. This section will discuss the standpoint or theoretical position of the research study. Durkheim (1938) suggested that all preconceptions should be eradicated when undertaking research (Bryman, 2004). However there is growing acknowledgement that research cannot be value free as illustrated in figure 2.

It is understood that the approach taken to research is not a neutral value-free process, the researcher starts with certain interests and general concepts that

are brought to the study (Charmaz, 1995). If we take the earlier example of the Black Report discussed in section 2.5.1. The author, Peter Townsend had a commitment to research around the needs of the powerless, prior to the Black Report, undertaking studies of the elderly and the poor (LSE, 1992). Another example of non-neutral research is connected to the funding body (Irving and English, 2008) in this case CLAHRC NWC (see section 2.5). The overarching theme of health inequalities was specified for all funded projects, resulting in the formulation of relevant objectives and design.

The values of the researcher play a role in the choice of topic and the methods chosen. It is therefore necessary to briefly outline the values and motivation for undertaking the topic of this thesis. Prior to undertaking this research study, I had a role within the research arm of the NHS supporting research in primary care. International and national research projects were placed on a portfolio of studies that were facilitated or managed locally. Predominantly the studies were clinical trials that had received funding in line with government priorities and disease groups such as Diabetes, Stroke, Heart Disease and Cancer. It was during this time that the combination of undertaking a Masters degree in research methods and an asbestos diagnosis of a relative lead to an awareness of the power within the research agenda and subsequently the setting of research priorities.

Central to the contemporary issues around asbestos-related conditions was the role or lack of role that research had subsequently played in progressing any sort of treatment for people with such diagnoses. The notion of the vast differences between mesothelioma (a cancer specific to asbestos) in terms of its stagnation for prospective treatments compared to other cancers,

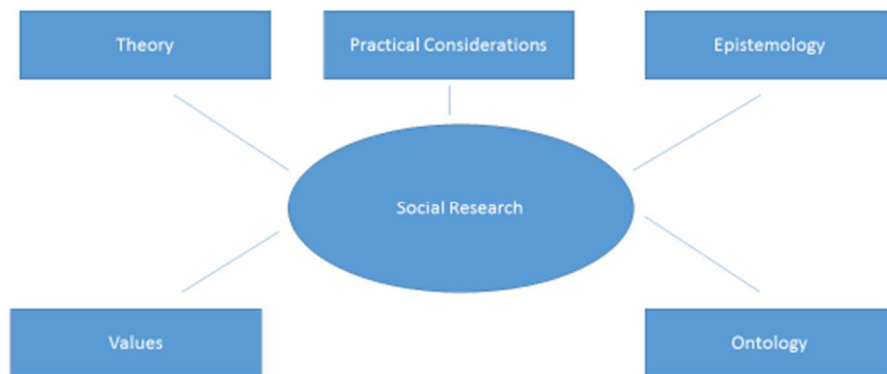
illuminated the issue of priority setting with regards to the type of research commissioned. The work of Professor Ray Donnelly highlighting similar issues regarding the lack of funding for lung cancer research compared to other types of cancer coined the phrase Cinderella cancer for this particular diagnosis (Donnelly, 2006).

During the roll-out of national service frameworks for heart disease (Dept Health and Social Care, 2000) there were debates in the organisation I then worked for regarding the lack of focus from central government on Chronic Obstructive Pulmonary Disease (COPD), common in working class communities where I was then based, with a history of mining and industry.

More recently the notion of the disparity between conditions was highlighted during the recent general election (The Guardian, 22<sup>nd</sup> May 2017) where a contentious area of debate referred to the “dementia tax” that promoted the notion that people with cancer receive funding and treatment on the NHS where dementia, an incurable illness relies on means tested social care support. In the past it was suggested that a difference between treatment of cancer and alzheimers disease was the limit of medical science (UK Government, 1999).

Power issues around research and the researched were pronounced when my ethics application working directly with people with asbestos terminal conditions was the focus of intense scrutiny by the research ethics committee. Their terminal conditions were the issue of debate around the appropriateness of involving them in research, despite a lack of research on this topic.

**Figure 2: Influences on Social Research, Bryman 2004**



The ethics process acting in the guise of protection, potentially excluding an already overlooked population in the research domain. Therefore my personal motivation for any research topic would not only be to pursue a gap in research but to address research for the benefit of a disenfranchised population group. This would involve working with hard to reach groups, also referred to as underdogs, with the objective of involving marginal groups (Lumsden, 2012).

People using day care in the community and the scarcity of research described in section 2.5.2 above are one such group. Whilst the dominant debate in society around aging is around support for people in the community, the research funding is foremost aimed at biomedicine and clinical research, with social care research trailing behind. Therefore what is referred to as a tsunami of aging or burden of aging is overlooked from the lens of community or social care. Whilst studies may look at LTCs, it is the pathological nature of specific conditions that is the focus rather than quality of life associated with it. The chosen topic therefore addresses the concept of a neglected area: multiple LTCs and focuses on what support is already available within the community from the lens of the clients that use it. By understanding the impact of services on the people using them, it enables those considered to be on the margins of society, at risk of exclusion to be included.

The following section provides a greater understanding of the overall approach of the study design.

#### **2.5.4 Theoretical Underpinnings / Framework**

Ontology is concerned with what exists to be studied or known (Walliman, 2006). It influences the epistemological framework of a study (May and

Williams, 1998). Epistemology is the philosophy of knowledge, a way of explaining how we know what we know.

The ontological underpinning of this thesis is developed from constructivism which asserts that the categories used in the social world are produced through social interaction. This is in contrast to the ontological position of positivism whereby social categories exist independently from social actors. The basis for constructivism asserts that phenomena are not just constructed but are in a constant state of change (Bryman, 2004).

The epistemological framework is based on interpretivism whereby knowledge of the world is construed in different ways by different people (Walliman, 2006). Therefore, the researcher needs to understand the subjective meaning associated with the social action (Bryman, 2004). Critics of interpretivism suggest that viewing knowledge in this way prevents generalisability of findings.

However, it can be argued that interpretivism enables an understanding of the lived experience of individuals (Smith 1998) within the context of the social world, thereby creating assurances for more specific applicability of findings for other similar settings. As interpretivism is based on the interpretation of human experience, participation in the social world is a prerequisite to understanding its features (Williams and May, 1996). The knowledge created emerges from the interaction between researcher and the participants, with different interactions producing different results (Guba and Lincoln, 1989).

The co-production of knowledge is becoming more common within policy and research (Filipe et al, 2017). In fact the funding body for this project (CLAHRC

NWC) see section 2.5.) emphasises co-production through effective engagement of stakeholders across all activities (CLAHRC, 2018). There are challenges to this concept of knowledge production with different views and negotiations throughout the process. Power imbalances between stakeholders are common in practice during co-production, however it has the potential to move on from the often token level of involvement of some patient engagement strategies (Filipe et al, 2017). The central ethos of the study was to ensure it was participatory or inclusive of the population group that was deemed hard to reach. Further details of this are given in chapter 4.

Taking this approach, rather than rely on objective measures that may not reflect the client's perceptions of their conditions, the subjective measures enable the impact to be viewed from their perspective. The disability paradox suggests objective measures of health do not routinely correspond to people's perceptions of it and despite the presence of disease and disability, individuals still regard themselves to be healthy (Bootsma-van der Wiel et al 2001, von faber 2001, Rowe and Kahn 1998). Therefore, although disease increases with age, people within this age group experience high levels of wellbeing despite having one or more conditions or disease (Young, 2009).

The method of inquiry chosen to undertake the research and its framework for analysis, is based on the philosophy of pragmatism. Charles Sander Pierce is accredited with the inception of Pragmatism in the 1800s, brought into common use by William James and John Dewey in the first part of the 20<sup>th</sup> century and later coming into favour in the 1980s due to the work of Richard Rorty (Talissee et al, 2008). In pragmatism methods are chosen in order to answer the research question with the aim of generating knowledge for



practical application, as opposed to selecting methods in line with a particular paradigm: quantitative for positivism or qualitative interviews for interpretivism. In line with the principles of CLAHRC, the production of knowledge within the collaboration has the mission to apply research outcomes in practice so that health inequalities can be reduced and the health of the local population improved (CLAHRC, 2018).

For the purpose of this study, some guiding principles for the project were taken from the fourth generation evaluation by Guba and Lincoln (1989). Flowing from constructivist ontology and interpretivist epistemic foundations, it begins with the understanding that realities are constructed. It follows a joint collaborative process during which, relationships with stakeholders are negotiated and placed at the centre of the process. This includes discussing priorities and developing research questions. This is discussed in further detail in chapters 4 and 5.

## **2.6 Chapter Summary**

Day care finds itself in a position within the community to support older people who wish to age in place. However day care models are diverse and are evolving in response to recent legislation amid a climate of reduced budgets. As wider debates around the aging population continue, service use by people with LTCs continues to rise as the interface between health and social care is brought into sharp focus.

Services are under pressure to provide evidence regarding their impact by demonstrating outcomes for service users. Little is known about outcomes for day care service users. Where outcomes are known, the lack of model description means that it is difficult to replicate findings into practice. As the

service straddles both the preventative and respite models the aims and objectives of services may vary within the community. Through the lens of health inequalities, accessibility to services may arise due to the diversity of the provision available.

In line with the theoretical framework, a greater understanding of the experiences of older people using day care services is to be investigated. The lack of focus around multiple long terms conditions despite its prominence in this age group requires attention. The following chapter will explore evidence in the literature from the perspective of the users or clients by conducting a systematic review.

## **3. Systematic Review**

### **3.1 Introduction**

This chapter describes the findings from a systematic review undertaken in 2015 to establish the current evidence in the literature applicable to day care and outcomes for people with multiple LTCs. Searches were repeated in 2018 to review evidence published since then for the purpose of this thesis. In line with the theoretical approach of the project, a decision was taken not to merely rely on the literature base to develop the project. This was for theoretical and practical reasons. Foucault described how some beliefs, concepts and ideas become dominant or accepted as reality and how some knowledge is privileged over others (Foucault, 1980). Taking this into account the literature published from academia could be perceived as part of the hierarchy of knowledge.

Therefore, other forms of knowledge were also incorporated into the orientation of the project. Chapter 4, describes the simultaneous efforts to engage with day care services currently operating in the climate described in section 2.4. From a theoretical point of view, this was to ensure forms of privileged knowledge did not outweigh situated knowledge from the providers and users of day care. This also ensured from a practical point of view that the study was designed appropriately around current service provision, rather than a theoretical study with little applicability in the field.

This chapter describes the findings from the systematic review. Previous reviews (Fields et al, 2014 and Mason et al 2007) explored day care for older people as a generic population. However, due to the increasing prevalence of

LTCs in the older population group, the review that forms this thesis, focuses on day care's role in supporting people with LTCs and reviews outcomes for participants and their carers. It explores day care across all provider settings from social care models through to palliative care day services, to encompass the range of sectors now found throughout the UK. In addition, a number of studies captured generic services as opposed to interventions within the day care provision. Although respite function is acknowledged, less is known about interventions such as educational programmes or support groups. Previously, a systematic review (Mason et al, 2007) of the effectiveness and cost effectiveness of different models of all types of respite care for frail and older people and their carers included day care as a form of respite. It established limited findings in terms of benefits beyond satisfaction amongst carers. It also found that the cost of day care was on level with usual care. It focused on quality of life of caregivers looking after patients' with alzheimers and dementia and therefore did not include people with other conditions.

### **3.2 Inclusion**

Inclusion criteria for this systematic review considered day care services provided external to the home and based across private sector, public sector and Voluntary or Charitable provision and evaluated outcomes for older people age 65+ either physical, psychological or social. In the UK access to day care services is embedded in the government's wider personalisation agenda, whereby individuals who qualify for their support have more control over the type of support they access. Papers from 2004 to 2015 were retrieved as it was felt that the current personalisation agenda and development of current UK health and social care policies originated from around 2004, for

example the National Service Framework for people with LTCs and in social care, personal budgets for people with disabilities also originated around this time. Studies were included if published in English, as funding for translational services was not available. As mentioned in section 3.1 the searches were repeated in 2018 and retrieved a further eight studies.

### **3.3 Exclusion**

In the UK a large amount of resource has been focussed on cancer services, including respite care for people with cancer. It was decided to exclude studies that only included cancer patients to avoid distortion of results from palliative care or respite cancer care. Palliative day care settings were included but only if there was a non- cancer focus. The illness trajectory of people with LTCs compared with cancer are different, with models of cancer care not suitable for use with people LTCs (Kendall, 2015). Exclusion of solely cancer focused studies would enable the concept of LTCs to be explored and viewed more clearly.

The review included international articles and there were challenges in determining inclusion criteria with regards to service models. Within international literature, some day centre services, upon closer scrutiny were day hospitals or rehabilitation centres. It was felt that for day services in this setting, participants attended for short term interventions associated with their physical, social or psychological needs. Day care models within the UK are accessed on an ongoing basis, rather than a short term intervention. Therefore, the research team discussed such papers and day hospital or rehabilitation day settings were later excluded.

### **3.4 Search Criteria / Methods**

Searches were undertaken during March and May 2015 and repeated in 2018, using the following databases: web of science, pubmed, medline, cinahl, psych INFO, Cochrane Review Library, Scopus and Social Care online. Charitable websites were also perused for relevant articles and manual checking of article references were undertaken. The search terms used were: 'day care' or 'day service' or 'day centre' or 'social day care' or 'palliative day care' or 'Voluntary day care' or 'senior centre' or 'respite care' AND 'older people' or 'elderly' or 'seniors' or 'pensioners' or 'elderly frail' AND 'long term conditions' or 'chronic conditions' or 'complex conditions' or 'comorbidity' or 'multimorbidity' or 'dual diagnosis'. Additional searches were also undertaken for common single long term conditions such as respiratory disease and heart failure. Reference to long term settings were excluded. Keywords were added for day care for older people in rural or urban settings.

### **3.5 Selection of included studies**

Searches were undertaken and titles scanned for relevance with those meeting criteria reviewed at abstract level. Studies were then selected by myself and discussed with the supervisory team for inclusion to be agreed.

#### **3.5.1 Data Extraction and Analysis**

Each included study was summarised and data extraction undertaken, with particular interest taken in the types of outcomes for older people, the philosophy of the day care provider, the types of LTCs and how they were addressed in the study, and if rural or urban day care was included.

The quality of the included studies was also assessed using the system developed by Hawker and Payne (2002) for reviews including studies using a

diversity of methods. Studies were scored by myself and supervisors using the nine criteria using the scoring system; good 4, fair 3, poor 2, very poor 1. Where different aspects of the same study was described in more than one paper, the study was scored and treated as a separate study.

Data extraction and analysis were undertaken by myself. No attempt has been made to combine the results as a wider range of interventions and settings made this inappropriate.

## **3.6 Results**

### **3.6.1 Search results**

The initial search terms yielded 916 titles (not including duplicates) and further searches yielded no additional new papers. In line with the search strategy the initial articles were reduced to 34 that were selected for the systematic review (see figure 3 for more detail). The repeated search in 2018 revealed a further eight articles. All potentially relevant articles were written in English. The most common reasons for exclusion were the large number of descriptive studies that did not look at outcomes for participants or carers (59%). The primary objective of a number of studies focussed on the needs of people using day care. So for example, the day care settings was used as a strategy to access the older population regarding age related issues (17%). There were also a number of studies that included respite day care amongst other forms of overnight or short term day care placements but were excluded as they were solely focussed on the needs of cancer patients (23%).

## **3.7 Characteristics of included studies**

Thirty four studies were eventually chosen for further scrutiny, eight studies from the updated review bring the total illustrated in Table 1 to 42 studies.

Seven studies were qualitative and 35 were quantitative from 13 countries (US, Canada, UK, India, Netherlands, Norway, Israel, Italy, Spain, Finland, Japan, South Korea, Sweden Taiwan, Malta and Germany). For studies where different aspects of the research were published separately, the published studies were assessed individually, see Lecovich et al (2012, 2013A and 2013B) and Embrey (2009A and 2009B).

Two UK studies were based within the palliative day care setting and one study included Green Care Farms in the Netherlands. The remainder of the studies were based in adult social care or day service settings. Studies ranged from large scale quantitative studies and small scale qualitative studies with population size of studies ranging from 1673 frail elderly people in a prospective cohort study (Kuzuya, 2006) to 15 patients in a qualitative study of caregivers of Mexican Americans attending day care for the elderly frail (Valadez, 2005). A number of studies compared day care attendance with non attendance at day care (Lecovich & Biderman, 2012, 2013a & 2013b, Jacob et al 2007, Bilotta, 2010, Schacke & Zank 2006, Schmitt et al 2010 and Kelly, 2017). Other examples compared new interventions with usual day care De Bruin (2011), Pitkala (2009), Drees et al (2004), Horowitz et al (2004).

### **3.8 Quality**

The quality of studies was assessed using the Hawker and Payne method for reviews containing a range of methods (Hawker and Payne, 2002). This method assesses nine aspects of each study, for example: abstract and title; introduction and aims; method and data; sampling; data analysis; ethics and bias; results; transferability and implications and practice. Each component



**Table 1: Systematic Review – Table of Selected Studies**

Author & Year	Country	Title	Method	Numbers	Population	Summary Findings	Quality Score
Bartfay & Bartfay (2013)	Canada	Quality of life outcomes among alzheimers disease (AD) family caregivers following community based intervention.	Quantitative	62	Carers for alzheimers and non alzheimers patients	Cross sectional comparative design to examine the impact of 2 community based interventions on carers qol; carer support groups and adult day care. <b>Caregivers of AD clients who use community based interventions enjoyed similar levels of qol as caregivers of non-AD clients.</b>	36
Bilotta 2010	Italy	Day care (DC) centre attendance and quality of life in depressed older adults living the community	Quant	149	Age 70+ yrs Depressed older adults	Cross sectional study to find out whether the attendance at day care was associated with quality of life in community dwelling older adults suffering from a depressive order without dementia. <b>Participants attending DC at least once per week had a higher mean EuroQol VAS score than non-attendants.</b>	31
Boen 2012	Norway	A randomized control trial of senior centre group support programme and preventing depression in elderly people living at home in Norway	Quant – RCT compared with no d.c.	138	Age 65+ Light depression	RCT comparing senior centre intervention compared with control group to examine the effect on comparing depression, increasing social support and self related health and satisfaction with life. <b>Social support increased in both groups but greatest in intervention group. Level of depression decreased in both groups but more so in control. Decrease in life satisfaction in both</b>	36

						<b>groups, largest decrease among controls.</b>	
Dabelko-Schoeny & King 2010	USA	In their own words: Participants Perceptions of the impact of adult day services.	Qualitative	28	Mean age 78yrs  absence of severe cog. Decline.	Semi structured interviews to gain an understanding of the experiences of older people after attending day care for 3 months. <b>Participants experience at day care associated with perceived improvements in psychosocial well-being and a perceived decrease in burden or dependence on the caregiver.</b>	35
De Bruin 2011	Netherlands	Comparing day care green care farms and at regular day care facilities with regard to their effects on functional performance of community-dwelling older people with the dementia.	Quant	88	Age 65+ Older people with dementia	Observational cohort study comparing Green Care Farms with Regular Day Care. <b>No significant change over time in functional performance, the number of diseases and the number of medications was observed</b>	32
Drees 2004	Netherlands	Effects of meeting centre support programme on feelings of competence of family carers and delay of institutionalisation of people with dementia	Quant	54	Carers of people with mild to moderate dementia	Quasi experimental design – pre-test/post test control group with matched groups comparing meeting centres (MC) and regular day care (RDC) centres.  <b>After seven months the carers in the MC compared to the RDC showed a moderate positive effect of the feeling of competence.</b>	34

Embrey 2009A	UK	Exploring the lived experience of palliative care for people with MS part 2	Qual	36	MS	Phenomenological approach, non probability sampling with grand tour approach sampling, open ended interviews. <b>Patient's views of therapeutic interventions in day care alleviated symptoms, enabled achievement, fun and distraction from symptoms and optimism.</b>	32
Embrey 2009B	UK	Exploring the lived experience of palliative care for people with MS part 3	Qual	36	MS	Phenomenological approach, non probability sampling with grand tour approach sampling, open ended interviews. <b>Feeling relaxed positive and self confident, put yourself back in the world but also leave your own life away.</b>	27
Femia 2007	U.S.	Impact of adult day services in behavioural and psychological symptoms of dementia	Quant	133	Dementia Pts and Carers	Quasi experimental design to compare group of people with dementia attending day care and those not using these services. <b>Relationship between day care use and caregivers' report of fewer nighttime sleep-related problems for their People with Dementia.</b>	36
Fitzpatrick 2005	Canada	Social support factors and health among senior center population in southern ontario, canada	Quant	186	Mean age 72.5 yrs	Self administered questionnaire with people attending day care, examining the impact the support role that friends or staff played on perceived mental and physical health. <b>Caregiving is significantly related to physical health, how respondents feel</b>	32

						<b>in general and happiness with personal life.</b>	
Frosch et al 2012	U.S.	Activating Seniors to improve chronic disease care: results from a pilot intervention study.	Quant	116		Two group quasi experimental study examining impact of video screening on health activation, one group incentivised to attend. <b>At 6 month follow up, participants from either center who attended three or more group screenings reported significantly greater activation.</b>	35
Garcia-Martin 2015	Spain	A structural model of the effects of organized leisure activities on the well being of elder adults in Spain.	Quant	122	Mean age 67.6yrs	Comparative study of users of day care accessing 4 activity groups compared with control group not attending day care. <b>Participation in activity groups contributes to reducing the level of depression and loneliness in the participants and increase their level of life satisfaction and perceived control in their lives.</b>	29
Gitlin 2006	U.S.	Enhancing quality of life of families who use adult day services: short and long term effects of the adult day services program	Quant	129	Carers	Quasi experimental design comparing and enhanced form of day care (DCplus) supporting carers and regular day care. <b>At 3 months Dcplus carers reported less depression, improved confidence managing behaviours and enhanced wellbeing compared with controls.</b>	36
Haeflervan, 2016	The Netherlands	Is socially integrated community day care for people with dementia associated	Quantitative	69 75 35	People with dementia Carers	Survey <b>People with Dementia were more positive about the communication and listening skills of staff and the</b>	31

		with higher user satisfaction and a higher job satisfaction of staff compared to nursing home-based day care?			Staff	<b>atmosphere and activities at the community based centre than the nursing home day centre. Caregivers valued the communication and expertise of staff at the community based centre.</b>	
Higgins 2005	U.S.	Impact of an activities based adult dementia care program	Quant	37	Dementia Mean age 77	Longitudinal study examining the impact of educational program at modern day care facility on quality of life. <b>Patients reported no change in quality of life.</b>	32
Horowitz BP, 2004	U.S.	Promoting well being and engagement in life through occupational therapy life redesign: a pilot study with adult day programs	Quant	28	Mean age 74.3 yrs	Randomized comparison of 16 week group orientated program and day care examining its impact on physical functioning and wellbeing  <b>No statistical differences were found between groups at follow up. Experimental group showed favourable results on role functioning, bodily pain and general health.</b>	27
Jacob 2007	India	The effect of community based daycare on mental health and quality of life in rural south India	Quant	41	Mean 70 yrs	Comparative study of the impact of day care on quality of life and cognitive impairment for users and non users of day care. <b>There was significant reduction in psychiatric morbidity and improvement in quality of life scores at 3 months for subjects who attended the program.</b>	27

Karania, 2017	UK	Evaluation of Age & Dementia Friendly Gymnastics Programme	Qual	64		Evaluation of an impact of a bilaterally assymetric gymnastics-based programme on older people participating in a care home and day centre setting <b>Older people participating in the programme showed a demonstrable improvement with aspects of their physical, emotional and cognitive ability. Older people with mild to advanced forms of dementia appeared to benefit the most.</b>	23
Kelly, 2015	Canada	The effect of adult day program attendance on emergency room registrations, hospital admissions and days in hospital: a propensity-matching study	Quantitative	812	Mean 81 yrs	Comparison of attendance at hospital who attend day care compared with non attendance at day care <b>Analysis revealed significantly lower mean 100- day rates of emergency room registrations, hospital admissions and days in hospital for attendees compared to matched non attendees.</b>	
Kuzuya 2006	Japan	Day care service use is associated with lower mortality in community dwelling frail older people	Quant	1673		Prospective Cohort examining day care use and mortality in community dwelling frail older people. <b>Multi-variate cox regression model showed that day care service use was associated with reduction in mortality.</b>	35
Lecovich 2012	Israel	Attendance in adult day centers and its relation to loneliness among frail older adults.	Quant	817	Mean 78 yrs	Case controlled study examining loneliness of day care users and non users. <b>No significant differences were found between users and non users of day care centers in the level of loneliness.</b>	36

Loecovich 2013A	Israel	Use of adult care centers: Do they offset utilization of health care services	Quant	800	Mean 78yrs	Case controlled study examining utilisation of services of user and non users of day care. <b>Utilization of health care services was connected with morbidity rather than day care use.</b>	34
Lecovich 2013B	Israel	Quality of life among disabled older adults without cognitive impairment and its relation to attendance in day care centres	Quant	817	Mean 78 years	Case controlled study examining quality of life for users and non users of day care. <b>Quality of life was found to be significantly related to the use of day centres but length and frequency of attendance were insignificant in explaining quality of life among users of day care centres.</b>	31
Lin, 2015	Taiwan	The effects of Tai Chi in conjunction with thera-band resistance exercise on functional fitness and muscle strength among community-based older people	Cluster randomised control trial	138	Mean 74 years	Older people assigned to an exercise group or control group, twice weekly for 16 weeks. <b>After receiving thera-band resistance exercise, interventions participants displayed a significant increase in muscle strength of upper and lower extremities.</b>	33
Mavall and Thorslund 2007	Sweden	Does day care also provide for the caregiver?	Quant	51	Mean age 79yrs Dementia or memory probs.	Comparative study of carers residing with or not residing with the person with dementia, who attended day care. <b>Non co-residing caregivers whose relative dropped out of day care had higher level of depression, worry, overload and role captivity than the caregivers whose care recipient continued in day care.</b>	31

Mavall & Malmberg 2007	Sweden	Day care for persons with dementia	Quant	51	Mean age 79yrs Dementia or memory probs.	Prospective 12 month study examining the impact of those attending and those that dropped out of day care. <b>One third of people discontinued within 4 months and another third dropped out within 12 months. People with behavioural problems and those who needed assistance with dressing and toileting discontinued earliest.</b>	29
Molzahn 2009	Canada	Quality of life associated with adult day centers	Qual	20	Pts & carers Pts 60-92 yrs Carers 50-82 yrs	Semi structured interviews with pairs of attendees at day care and their carers. <b>Major categories emerged include physical health, well being, social networks/relationships, aging in place, safety, respite, activation, respect, activation, respect and inclusion.</b>	34
Mossello 2008	Italy	Day care for older dementia patients: favourable effects on behavioural and psychological symptoms and caregiver stress	Quant	60	Dementia	Case controlled study comparing users of day care and non users of day care on behaviour and psychological symptoms and caregiver stress. <b>NPI score significantly reduced in day care with a reduction in psychotropic drugs prescription but increased in home care.</b>	32
Park, 2017	USA	A Pilot Randomized Controlled Trial of the Effects of Chair Yoga on Pain and Physical Function Among Community-	Quantitative	131	Mean 75 years	Two arm randomized control trial. Participants assigned to chair yoga or health education program <b>The chair yoga group showed greater reduction in pain interference during</b>	31



		Dwelling Older Adults with Lower Extremity Osteoarthritis				<b>intervention sustained through 3 months.</b>	
Pitkala 2009	Finland	Effects of psychological group rehabilitation on health, use of health care services and mortality of older persons suffering from loneliness: a randomised controlled trial	Quant	235	Mean age 80yrs	Randomised Controlled Trial comparing those assigned into group activities designed around therapeutic interventions with usual day care. <b>2 years survival was 97% in the intervening group and 90% in the control group. The intervention group showed significant improvement in subjective health, this resulting in significantly lower health care costs during follow up.</b>	35
Ron 2007	Israel	Self esteem among elderly people receiving care insurance at home and at day centers for the elderly	Quant	300	Mean age 74yrs	Comparison of two day care and home care and its impact on self esteem. <b>Self esteem higher attending day care than at home.</b>	33
Schacke & Zank 2006	Germany	Measuring the effectiveness of adult day care as a facility to support family caregivers of dementia patients	Quant	77	Carers Dementia Mean age 59yrs	Longitudinal study comparing users and non users of day care. <b>Use of day care significantly reduced conflicts between caregiving and job requirements, caregiving and family needs and recreational constrictions.</b>	31
Schmitt et al 2010	U.S.	Adult Day Health Centre Participation and health related quality of life	Quant	124	Age 55yrs +	Case controlled prospective study comparing user and non users of day care. <b>Physical scores for day care attendees improved compared with the non users. Emotional scores improved for</b>	36

						<b>day care attendees but declined for non attendees.</b>	
Shapira 2007	Israel	Promoting older adults' wellbeing through internet training use.	Quant	22	Mean age 80yrs	Quasi experimental research design comparing the impact of those utilising computer training and those not on their wellbeing. <b>Significant improvement among participants in the intervention group in all measures except physical functioning whereas deterioration in all measures was detected in the comparison group.</b>	32
Smeets 2012	Netherlands	Respite care after acquired brain injury: the wellbeing of caregivers and patients	Quant	108	Paired patient and carers Acquired Brain Injury	Cross sectional cohort study of patients with Acquired Brain Injury attending day care. <b>Caregiver well being was positively correlated with a high sense of mastery of caregivers and patients and low passive coping of the patient.</b>	35
Song, 2017	South Korea	Seniors centre-based health intervention programmes in the US and South Korea a systematic review	Systematic Review	22 studies		Systematic review of health programmes provided at day centres <b>Health interventions resulted in positive effects on senior centre participants knowledge, health behaviours, clinical indices and hospitalization rates.</b>	
Spiteri, 2016	Malta	What do older people learn from young people? Intergenerational learning in 'day centre' community settings in Malta	Qualitative			Focus Groups <b>The elderly see students as helping them on a practical level, by offering them insights that help them in modern day life.</b>	31

Tomita 2010	Japan	Impact of home and community based services on hospitalisation and institutionalisation among individuals eligible for long terms care insurance in Japan	Quant	1020	Mean age 71yrs	Retrospective cohort study comparing users of various community services, including day care and non users with regards to hospitalisation and institutionalisation. <b>Users of home and community based services were less likely than non users to be hospitalised or institutionalised.</b>	33
Tretteteig, 2017	Norway	The influence of day centres designed for people with dementia on family caregivers	Qualitative	17	Carers of people with dementia	In-depth interviews <b>Day care gave the carer a feeling of freedom and increased time available to be spent on their own needs, to be social and to work or do practical tasks undisturbed.</b>	32
Valadez 2005	U.S	Family caregivers of impoverished Mexican American elderly women: the perceived impact of adult day centers	Qual	15	Carers	Semi structured interviews examining the impact day care had on carers lives and that of their elderly parents. <b>Perceived positive effect on the elderly parent's physical and emotional states and the elderly parent caregiver relationship and the negative effects of stress associated with caregiving.</b>	35
Zarit 2013	U.S	The effects of adult services on family caregivers' daily stress	Quant	173	Carers of people with dementia	Telephone interviews with carers who used day care for respite, comparing stress on day care attended day and non attended days. <b>Day care use lowered anger and reduced impact of noncare stressors on depressive symptoms.</b>	36

Zarit 2011	U.S.	Effects of adult day care on daily stress of caregivers: w within person approach	Quant	121	Carers of people with dementia	Telephone interviews and daily diaries with carers who used day care for respite, comparing stress on day care attended day and non attended days. <b>Total exposure to stressors and stress appraisals decreased significantly over time at day care days compared with non day care days.</b>	36
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is assessed using the scoring system good (4), Fair (3), poor (2) and very poor (1). The quality score for articles within the review ranged from 23 to 36.

### **3.9 Outcomes**

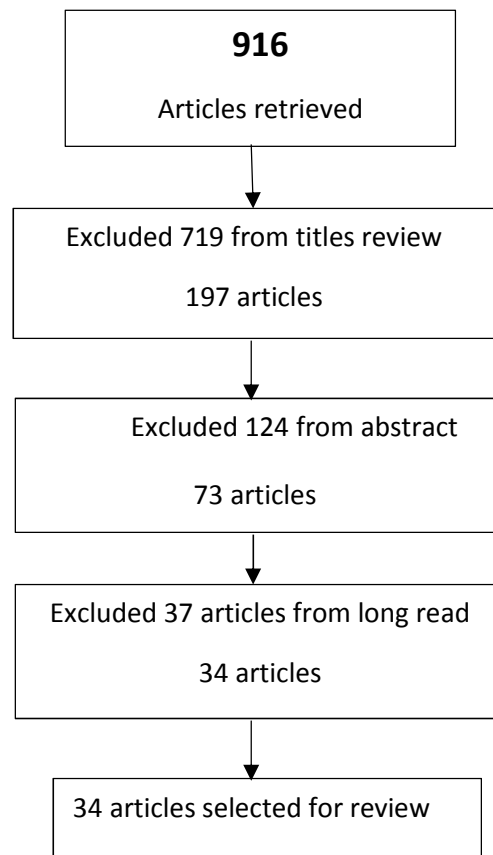
The findings discussed are organised into themes in terms of the types of outcomes revealed. The outcomes were derived following the review of themes arising from the data extraction phase of the systematic review. Outcomes were reviewed and synthesised together for the following themes. Respite; Carer Burden; Service Utilisation and Self Management; Psychological outcomes; Social Isolation; Physical Functioning.

#### **3.9.1 Respite**

Half of the studies (16) within this review include or refer to the respite function of day care. The aim of the day care studied was to provide carers with time away from the person cared for.

Eight studies related to impact of day care on carers (Bartfay & Bartfay 2013; Gitlin 2006; Mavall & Thorslund 2006; Schacke and Zank 2006; Valediez 2005; Zarit 2011, Zarit 2013 and Tretteteig, 2017 ). A further two studies specifically refer to the respite function from the patient's perspective (Embrey 2009a and Embrey 2009b), with a further eight studies including both the patient and the carer in the study population (Droes et al 2004, Femia et al 2007, Mavall & Malmberg 2007, Mavall & Thorslund 2007, Molzahn et al 2009, Mossello 2008, Smeets 2012 and Haeflen-van, 2016). It was evident that there is a particular focus on dementia and respite day care within the literature with ten of the 16 studies focussed only on dementia.

**Figure 3. Article selection overview**



Six studies explored respite care to reduce carer burden and assessed the support day care gives to the carers, discussed in more detail in the next section below. It was a particular day care program with emphasis on supporting or training carers that provided some positive results. Studies which found positive on day care for carers were mainly small qualitative studies (Embrey 2009a , Embrey 2009b, Valadez 2005, Molzahn et al 2009). Participants felt day care provided regular intervention before crisis developed (Molzahn, 2009).

The quantitative studies of respite did not find any significance in quality of life for those attending day care (Bartfay & Bartfay, 2013, Mavall & Malmberg 2007, Mavall & Thorslund 2007, Smeets 2012).

Smeets (2012) investigated satisfaction with respite care and wellbeing of informal caregivers and patients with Acquired Brain Injury using day care activities and found satisfaction with respite was present but now associated with "life satisfaction".

For some population groups, such as Alzheimers or Dementia, there were difficulties using day care for behavioural issues (Mavall & Thorslund, 2006, Mavall & Malberg, 2007 and Bartfay & Bartfay, 2013). Mavall & Thorslund (2006) and Mavall & Malmberg (2007) suggested carers of those who opted out of day care had higher levels of worry and overload than those who continued. It was found that it was more common for those with behavioural problems associated with alzheimers or dementia to opt out. Carers cited the issue of getting ready prior to the session as a barrier to attending. Benefits for those continuing with day care included respite for carers.

There was evidence from other studies that day care improved carers coping mechanisms due to the respite function of day care. Valadez et al (2005) found that carers felt less anxious and worried when they were not with their relative in day care and this improved relationships when they were together. Embrey (2009B), in a UK study of 36 participants attending a palliative day care unit for people with Multiple Sclerosis highlighted the importance of partners getting time out from their caring responsibilities.

### **3.9.2 Carer Burden**

It is expected that the respite function of day care will decrease feelings of carer burden. Previously Zarit, Stephens, Townsend and Greene (1998) found caregivers in the USA, where the person with dementia attended day care for minimum of twice a week for 3 months, benefited significantly in terms of reducing caregiver depression and caregiver burden.

Six comparative studies utilising quantitative methodologies, explored the issue of carer burden. Five included only dementia whilst in the sixth (Gitlin, 2006) although including a wider population, 58% of the study participants had dementia as a primary diagnosis. There are limited findings that day care can reduce carer burden, improve carer competence and confidence. The main limitation of findings relate to the lack of randomisation to day care. Although the studies all include comparative design, participants for all studies are enrolled following attendance at a participating day care centre. Two studies (Femia, 2007, and Schacke and Zank 2006) compared day care and non day care users. Another compared day care with home care (Mosello, 2008). Two studies (Droes et al, 2004 and Gitlin, 2006) compared regular day



care use with an enhanced day care service that provided support and case management for carers

Droes et al (2004) investigated whether meeting centre support programmes can reduce carer burden and delay of institutionalisation mild to moderate dementia. Meeting Centre programme provided bi weekly discussion groups for carers whilst the care recipient accessed activities up to 3 days per week compared with regular day care, that did not include support for the carer in its provision. Results illustrated that carer burden was not reduced by the programme. However, a significant difference was found in carer competence, with carers using the meeting centre programme feeling more competent than those using regular day care ( $p=0.04$ ). There appeared to be a delay of entry into nursing home by those using the meeting centre programme ( $p=0.027$ ). The study sample however was small with a limited power.

Similarly, Gitlin (2006) compared adult day service plus (day care plus social work advice, case management for referrals, education and counselling for carer) and regular day care for a range of conditions but predominantly dementia. The study recruited 129 caregivers across three centres. At 3 month follow up, carers reported less depression ( $p=0.016$ ) and increased confidence at managing behaviours of the people they cared for ( $p=0.013$ ) and reported enhanced well being ( $p=0.001$ ).

There is evidence in particular for dementia patients that day care can reduce carer burden (Zarit, 2013, Femia 2007, Mosello 2008). Zarit found caregivers experienced lower exposure to care related stress on days when the people they cared for attended day care. They also experienced more positive experiences and their anger rates lowered. Care related stressor and non

care related stressors were compared. It was found that there was an association between care related stressors and depression; however for those attending day care more frequently, whilst there was an increase in care related stressors it did not increase when compared with those attending for fewer days.

Femia (2007) found a positive relationship between adult day service use and carers reporting fewer night time sleep related problems. There was also a trend, though not significant, between reduced depressive symptoms and agitated behaviour for those attending day care. Mosello (2008) found people with dementia attending day care, experienced a decrease in symptoms such as delusions, agitation, anxiety and disinhibition that in turn reduced caregiver burden when compared to those only receiving home care. Behavioural and psychological symptoms of dementia decreased in the day care group and increased in the control group ( $p < 0.001$ ) over the same two month period. The sample size was small with 30 participants in each group.

Schacke & Zank (2006) found the use of day care was significant ( $p = 0.41$ ) in alleviating care giver stress for those who affected by the role conflict caregiving brings. It enabled a better compatibility of carer's roles in terms of their other commitments to family or jobs. The conflicts between caring and jobs or family, got worse over time for those not using day care. Sample size and attrition rates were also difficult with this study. 77 people were recruited, with 37 attending day care and 40 assigned to the control group. At the 9 month measure 48.6% of the intervention group and 45% of the control group had dropped out of the study due to illness or entering a care home.

### **3.9.3 Service Utilisation and Self Management**

Two aspects of service demand emerged from the articles selected. One aspect relates to the notion that day care provides the opportunity to delay placements into nursing home or long terms care, and reduces burden on other services considered by three studies (Tomito et al, 2010, Lecovich & Biderman 2013A, Pitkala et al 2009 and Kelly 2015). The other notion is that day care can act as a gateway to other services, facilitating additional support for families with LTCs in terms of self-management of conditions. For people with LTCs day care may promote autonomy, with the impact of this revealed by six studies (Frosch et al 2012, Higgin et al 2005, Valadez et al 2005, Embrey 2009A Embrey 2009B, Garcia Martin et al 2015).

Two studies (Tomito et al, 2010 and Pitkala et al 2009 ) established an impact of service utilisation in terms of decreasing use of services. A further two (Lecovich & Biderman, 2013 and Kelly, 2015) showed a decline in the use of services when compared with non users of day care. Three large studies, Tomito et al 2010 including 1020 participants and Lecovich & Biderman 2013, including 800 people whilst Lecovich and Biderman studied 400 matched pairs of users of day care and non users (total 800) found that visits to specialists declined in the group using day care and in patient admissions. However, analysis also showed variances in the two groups characteristics with those attending day care having lower socio-economic status compared to those who did not.

Tomito et al (2010) in a large retrospective study from Japan, collected data for 1020 participants over an eight year period and analysed the use of home and community based services on the hospitalisation and institutionalisation

of people with LTCs. Those with low needs using day care were less likely to be institutionalised than non users (adjusted hazard ratio of 0.77 with a confidence interval of 95%). In Japan the Long Term Care Insurance Scheme categorised care and support needs into 6 categories, with light needs being the lowest level of support required. Therefore, there is some limited evidence that day care can reduce utilisation of other services. Pitkala et al (2009), in a randomised control study from Finland of 235 participant, established that the intervention group showed significant improvement in subjective health, associated with lower mortality and less use of health services after 2 years ( $p=0.039$ ).

The role of daycare as gateway to other services for people with long terms conditions was considered by three studies (Higgins et al 2015 , Frosch et al 2012 and Valadez et al 2005). Higgins et al (2005) looked at dementia patients attending a community based day care facility and whilst no difference in quality of life or a reduction in behaviour symptoms was established, there was an increase in carers accessing other support within the community, which was an aim of the intervention. Frosch et al (2012) provided people attending the day care facility with information videos sessions, themed around self-management of conditions, with participants discussing with primary care professional their conditions for more appropriate medications or activities following the intervention. Valadez et al (2005) highlighted that day care participants also received transport to other appointments, promoting better management of conditions and reducing carer anxiety with disruption to other commitments. Day care for these studies became the interface between social care and health, signposting to other services for appropriate support.

A further three studies (Embrey 2009A, Embrey 2009B, Garcia Martin et al 2015) highlighted that by taking part in activities during their time at day care they felt more in control of their own lives. The disability or illness had meant they felt less engaged with the world but day care had made them realise that they could still take part, interact with their peers and contribute to their community, increasing their life satisfaction. However the Embrey papers are from a small qualitative study of 36 participants.

#### **3.9.4 Psychological outcomes**

Associated with the level of control over life that day care can promote, the systematic review revealed thirteen studies, that revealed some evidence that taking part in day care promotes some psychological benefit. This ranged from the reduction of loneliness, depression and improvement of mental stimulation, self esteem and self worth. Again, methodological limitations mean that study designs such as cross sectional methodologies restrict an inference of effectiveness where significant results are present (Bilotta, 2010). Whilst a randomised control study (Pitkala 2009) established a reduction in loneliness for those attending day care, two further studies Lecovich, 2012 (a case control comparison) and a randomised control study looking at the effectiveness of day care on depression (Boen, 2012) did not report positive findings.

Pitkala 2009 focussed on people who presented as lonely and found subjective health improved more often in the intervention group ( $p=0.007$ ).

Eight studies looked at day care's role in relation to depression or mood (Boen et al, 2012 Garcia-Martin, 2015, Embrey 2009A, Embrey 2009B, Higgins, 2005, Valadez et al 2005, Bilotta 2010 and Horowitz et al 2007). Four studies

have low number of participants and are qualitative in design. Attendance at a day centre was associated with improved quality of life ( $p=0.019$ ) for people living in the community with depressive disorder without dementia compared with those who did not attend (Bilotta 2010). Horowitz et al (2007) also found that although not statistically significant there were lower scores for depression in the experiment group attending day care. Garcia Martin et al (2015) found that activities including maintenance exercise, handcrafts and art at the day centre reduced depression and loneliness. However, a randomised control trial increasing social support did not prevent depression and levels increased in both intervention and control group, (Boen et al 2012).

Carer's perceived change in mood of the family member's they cared for was attributed to socialisation at the day care facility (Valadez et al 2005) and reported informally it decreased sense of isolation of patients and carers alike (Higgins, 2005). Ron (2007) in a study comparing self esteem of those attending day care and those receiving services within the home and found those attending day care reported being less lonely and their self esteem was higher (Ron, 2007). Lecovich and Biderman (2012) did not find a difference in the levels of loneliness when using day care and found that loneliness the same when considering length of day care attendance and frequency of visits.

For dementia patients, Mosello (2009) assessed whether day care could reduce behavioural and psychological symptoms for older dementia patients. There was a reduction in the number of psychotropic drugs used by those attending day care when compared against home care ( $p=0.044$ ).

### **3.9.5 Health and general wellbeing**

A small number of studies (six) explored health and well being outcomes for those attending day care. Four reported some effect, but two studies did not establish any improvement. Pitkala (2009) randomised people into activity groups relating to their interests and found in addition to differences in utilisation of services as already discussed, scores for subjective health also improved for the intervention group with mortality lowered. Dabelko-Schoeny and King (2010), using qualitative methodology found participants identified positively with included social connectedness with other participants, empowering relationships with the staff and enjoyment of the social activities. Participants attributed these outcomes their perceived sense of increased psychosocial wellbeing and decreased dependence and burden on caregiver. Lecovich (2013B) also found that users of adult day care reported higher levels of quality of life in all dimensions and overall quality of life compared to non users. However as a cross sectional study this cannot prove causality between day care use and the high levels of quality of life.

Jacob et al (2007) studied elderly people attending traditional day care services which provided a mix of social activities, occupational therapy and meals. The group were on the lower end of the socioeconomic scale and compared with those who did not opt to attend day care from the same socioeconomic group. There was an improvement in quality of life scores for attendees of day care and statistically significant improvement for psychological scores after 3 months of using day care. However, Higgins et al (2005) did not find any difference for behavioural symptoms for people with dementia. In addition, Mavall and Thorsland (2007) found no difference

between those who dropped out of day care or who continued in their service although the study design is exploratory in nature.

### **3.9.6 Physical Functioning**

Ten studies included physical functioning (physical health and mobility) outcomes for those attending day care services. There was limited evidence of improved physical functioning for those attending day care however studies were either small or non random samples, unable to illustrate causation. Frosch et al (2010), found that people who attended three or more groups reported significantly greater activation, more minutes walking, engaged in vigorous physical activity. Horowitz et al (2007) produced results favourable to physical function following an Occupational Therapy (OT) intervention, although numbers were very small so should be interpreted with caution. Valadez et al (2005) found that carers' subjective view of physical functioning for the people they cared for improved following activities undertaken at day care but is a qualitative study with 15 participants. A qualitative study, with 36 patients with multiple sclerosis examined the holistic approach to patients well being on the palliative day care setting. It brought positive physical outcomes for patients in terms of managing their symptoms such as pain, muscle spasms and cramps. It was also found that patients felt activities such as art improved their issues with dexterity due to MS symptoms (Embrey 2009A & Embrey 2009B).

Schmitt et al (2010) undertook measures of physical health for the study at enrolment and then again at 6 and 12 months. It was found that physical scores improved for those attending day care but declined for the control group (not attending day care, living in the community), in particular this was



noticeable at 12 months ( $p=0.01$ ). The authors of the study highlighted that the centre was designed for full disabled access within the centre therefore those attending may have a perception of improved physical symptoms when attending day care as the day care facility catered more for their disability. Lecovich (2012) found improved physical function for those using adult day care when compared with those who did not attend but it was found that it was not related to how often they attended. Green Care Farm are structured day care facilities in the Netherlands, whereby participants take part in walks, feeding animals and gardening with their counterparts. However, functional performance was not maintained or slowed down by attending green care farms rather than Regular Day Care Facilities (De Bruin, 2011).

The revised review, revealed two studies that looked at an exercise intervention on day care users. Karania (2017) evaluated a dementia friendly gymnastics programme, whilst Lin (2015) examined the effects of Tai Chi on functional fitness and muscle strength. Lin established that resistance exercise displayed improvements on most measures of the senior fitness test and Karania reported that people with mild to moderate stages of dementia benefited most from the intervention.

### **3.9.7 Multimorbidity**

Although search criteria included several terms intended to capture comorbidity and multimorbidity in the literature, studies rarely included LTCs and multimorbidities. There was also a dominance in studies looking at dementia with half of all studies focusing on dementia participants or their carers. Bilotta (2010) considered diseases that impact on depression such as lung disease, eye disease, heart disease and arthritis and Dabelko-Scoeny

(2010) reported that most participants had at least 2 conditions with diabetes, hypertension, CV disease, renal failure, arthritis and mild dementia.

Lecovich & Biderman (2013) explored comorbidity as a variable and concluded that it was a predictor for usage of other services. Pitkala (2009) used the Charleson comorbidity index (1987) as a measure that takes into account the number and severity of a wider range of illnesses. Although the subjective health and use of health services was significant in the intervention group and costs for health care higher for those in the control group, there is no further mention or discussion as to the role played by comorbidities.

De Bruin (2012) gives an overview of other conditions, providing examples of differences between the two groups one in regular day care and green care farms. In terms of mobility the main difference appears to be those in regular day care had more orthopaedic issues than those attending green care farms. Therefore an assumption could be made that those who were more physically active chose Green Care Farms.

Fitzpatrick et al (2005), collected and reported on comorbidities with 36% of study participants having arthritis and 31% having high blood pressure. However, although considered as a variable within the study for physical and mental health, the only variable that did show significance was that those who had higher income levels also reported better physical health. Schmitt (2010) stated that 60% of participants attending day care had 2 or more comorbidities and 47% of the control group.

Therefore, few studies considered multimorbidities as a variable, highlighting a gap in previous research in this area

### **3.9.8 Urban / Rural**

We were unable to find any studies which explored models of day care associated with rural or urban areas.

### **3.10 Discussion**

The review confirmed previous findings of a lack of research regarding the outcomes associated with day care and highlighted that despite the growing population of this age group and increased LTCs, little attention has been paid to this in the research field that focussed on day care. Very few studies provide detail on the type of activities to support those attending day care or the nature of the provision.

A range of Interventions, population group and settings meant that a combination of results was not possible. The review focussed on studies published in English. International models of health and social care presented some challenges when assessing day care models. Discussions between the research team ensured that careful consideration was given to ensure international models akin to day care were included. This review is the first to consider the outcomes of day care for older people with LTCs. As the number of comorbidities increases with age, day care presents an opportunity to support older people through a variety of interventions. However, there was a focus largely on the respite function of day care and not always in association with the impact for the participant, only the carer. There has been evidence previously regarding the benefit respite care brings to the carer.

This review established that half of studies looking at outcomes of day care considered the respite function that day care can provide. This perspective

does not always take into account the outcomes of participants whilst in attendance at day care. There is some evidence that associated with psychological benefits of attending day care for participants can inadvertently impact on carers mood and coping mechanisms. Day care can also integrate interventions to support carers whilst participants are attending day care, such as counselling and education improving carers coping strategies. Current policy promotes investment in services that can prevent costly interventions later including services promoting the quality of life of older people and their engagement with the community. Previously evidence has suggested that day care can reduce utilisation of other services (Wanless Review, 2006).

Building on the findings by Drees et al (2004), there is evidence that a meeting centre support programme for the elderly reduces placement into long term care facilities such as nursing homes. There is the potential whilst providing respite to also prevent crisis for family caregivers and thus admissions into hospital. However, studies looking at this aspect of day care are few and small in sample size.

There is limited evidence that day care interventions can impact on participants self management of symptoms both psychologically and in some palliative care settings physically. As the social isolation of the growing older population continues to be a public health concern, day care's impact on those who would be left vulnerable in the community should be explored in more detail. This review established a number of studies established day care improving psychological well being and reduced loneliness.

This review revealed an absence of studies addressing the particular needs arising from LTCs and comorbidity. As the population ages there may be the

assumption that comorbidities are a natural consequence of aging and therefore not reported. Older participants were deemed a generic group, without considering the diversity of needs that older people may have due to disability. There seems to be an assumption that disability is associated with aging without further examination of sub groups with this growing population group. In the articles around Green Care Farms (De Bruin 2011) there were predominantly more men attending the physical day care setting, supporting AGE UK (2011) and Manthorpe's (2014) finding that men prefer more active clubs than traditional day services in the UK. There is a gap in provision for elderly men and De Bruin (2011) highlighted in the Netherlands male users opt for more physical activities in line with traditional male identity. However it goes some way to illustrating the diversity of the day care sector, that should be considered in future studies in light of commissioning the third sector within the UK.

Future research should investigate outcomes for day care for particular groups of older people, particularly in view of the expected increase in multimorbidities. The current rise in the numbers of older people is greater in rural areas and there is lack of research within this area.

### **3.11 Conclusion**

This systematic review supports earlier findings that there is a dearth of research, both quantity and quality with respect to day care across all providers, social, palliative and Voluntary. Despite the expected prevalence of LTCs within this age group, this review confirms that little attention is given to the role of day care in supporting their specific needs. The findings suggest that future research should move away from viewing this population group as

a generic “older group” and refocus on the variety of needs arising through LTCs.

Whilst the findings regarding the impact of day care does suggest potential benefits for carers in terms of respite and an increase in some physical and psychological measures for those attending social day care, the lack of description regarding activities, models of care and location of settings such as the provider’s sector (social, independent, Charitable, Voluntary) or environment (rural or urban) do not allow impact to be fully measured and findings applied in practice. As the role of third sector organisations develops in the UK, there is little attention on the outcomes of day care across this sector both in the UK and internationally. There is a lack of focus regarding specific needs of the groups included in the studies forming part of this review. Studies do not look at outcomes in relation to an individual’s specific need. From a policy perspective, there seems to be attempts to assess the impact of day care services on social isolation, self esteem and loneliness of older people, building on previous work surrounding these issues with regards to mortality. However there are clear gaps to be addressed in future research. Absence of comorbidities in the findings should be addressed in future research in view of its prevalence in this population group. In addition the closer examination of the setting (rural or urban) and more description about service providers would benefit the future application of the research findings.

## **4. Setting the Scene**

### **4.1 Introduction**

The aim of this chapter is to describe the preparatory work undertaken in order to set the research question and design the study. Establishing relationships with gatekeepers and developing insider/outsider dynamic is not rewarded in the traditional research sense (Irving and English, 2008) and is often overlooked in research literature. This chapter provides a description of the process undertaken in order to engage with services so that the study would be viable.

The project benefited from preliminary work with day care services early on in the design phase of the research. The project developed using a pragmatic approach (Biesta, 2010). Services were engaged with early on in the process that later enabled a sequential approach to site selection (Sharp et al, 2012), discussed in chapter 5. By canvassing services during the first phase of the study, a two-way dialogue was established whereby issues arising through the systematic review could be explored whilst understanding issues relative to the field.

The literature highlighted within the systematic literature review, reported in chapter 3, day service studies often did not report the service models (Manthorpe 2014) making the replication of beneficial models impossible. It was clear during the early stages of the literature review, that the current climate within UK policy that affected day care was not reflected. Therefore, to rely solely on the literature would risk designing a project that may not be topical or relevant for services I may wish to engage with later.

This chapter provides an overview of findings from early engagement with services built into the research topic during the design phase. This consisted of early meetings with services to have informal discussions about issues topical to their service and a survey distributed to local day care providers to understand more about service provision. The information collated during these two steps and the systematic review were used to define the aims and objectives of the study, described in section 4.5.

## **4.2 Project Design - Collaboration with Day Care Services**

A major challenge for the project was the evolution of day care services during the time of the project design. Local day care providers were contacted to discuss the current state of play. Engaging with local services in this way enabled the project to develop using both insider knowledge (Frankham, 2009 ) from people with experience of day care, combined with more rigorous and robust forms of knowledge from the literature. The advantages of utilising direct experience (Beresford, 2002) in this way means the focus of the research undertaken and subsequent outcomes are more relevant to the services and service users as opposed to those studies designed by a professional researcher (Faulkner, 2005).

It is argued that the ownership of the process in this respect may ensure the likelihood of the research being implemented later (Fox 2003). Key considerations during the planning phase enable exploration around how to accommodate any issues providers may have in terms of time and funding (Fontera 2009 and Robson 1993). A benefit of this approach is that researchers bring an understanding of research techniques to the organisation that may be limited by lack of research knowledge or research expertise of



practitioners (Robson, 1993). The approach enables the researcher to mediate in these circumstances, addressing research points and foundations developed by the practitioners and service providers.

Day care services from the statutory, private, Charitable and Voluntary sector were contacted by phone and email. Six services were contacted: 2 statutory services, 1 independent company and 3 services from the Charitable and Voluntary sector. I explained that I had been awarded funding to look more closely at the impact of day care services for older people and their families. The response on the whole was positive and I was able to arrange some visits to discuss emerging issues in more detail.

I met with a service run by a local authority, a Charity and a Voluntary group whilst the service was operational. I met clients and staff or volunteers and took part in activities taking place. Information was gathered using an informal method of open questions with reflections written up later once away from the centre. During meetings with staff or volunteers the role of the day centre was discussed along with issues affecting the service and their clients. Staff or volunteers would then show me around the centre and introduce me to clients explaining how the service operated and activities that they offered and why. Example of question to services: "What would you say is the purpose of what you do at the centre"? and for attendees "Why do you come here to the centre"? The aim of this was to gather information pertinent to issues affecting day care currently, in particular to the clients and their families.

During my visits I was also invited to stay and join in activities with the clients either in a small group or a larger group. Clients attending the centre would at first ask me questions about where I was from and then go onto explain

why they attended and what they felt they enjoyed about the centre. This enabled me to understand the setting more and gather information pertinent to issues affecting day care currently, in particular to the clients and their families. The key message was around previous loneliness for a variety of reasons associated with aging such as bereavement, illness or relocation. Clear messages were provided about how the clients felt that by attending the day care their wellbeing had improved. Therefore, in terms of assessing outcomes from the clients' point of view the priority was around loneliness and health and wellbeing status.

I also met with a local commissioner of day care services which was dominated by discussion around local targets regarding falls prevention in the elderly. Following visits to the centres it was clear that their function was more than a vehicle for fall prevention strategy. The research would therefore be from the viewpoint of the providers, users and families rather than those who were in more powerful or superior positions (Lumsden, 2012).

This key step during the design phase enabled me to discuss some key themes from the systematic review, emerging matters relating to current policy and day care services operational procedures. During these early conversations it was clear that the long term future was uncertain for services. Services across all sectors appeared to be under pressure and were in the midst of managing the impact of the recent introduction of the Care Act 2014 (UK Gov, 2014). Therefore, the approach I would need to design to engage services during this period and methods chosen needed careful consideration. In practical terms, this meant that the organisations' capacity in terms of time would need to be considered when selecting methods (Fontera 2009 and

Robson 1993). Methods that may be too burdensome for services had to be avoided.

The systematic review highlighted the perception that a central theme of day care is to provide respite for family carers, confirmed by discussions with the local authority service and the Charity. However, a Voluntary service emphasised how they felt they enabled the community to monitor those deemed vulnerable and living alone rather than the benefit to carers.

This was due to the fact that many of the services users did not have any support at home or relatives to rely on. The manager of a charitable service also stated that the service was the only contact many of the service users had with people each week. All services felt a key aim was to prevent loneliness and reduce isolation for the clients attending, whilst supporting them to remain as independent as possible. It was perceived that this strategy would enable people to continue living in their own homes for as long as possible. On the basis of this input I could start planning the tools available (see section 5.3) to measure the impact that day care had on the people and their families using it.

The visits also enabled me to frame the population group more closely. Whilst clients having multiple LTCs was the focus of the project, the services did not use this phrase and clients were referred to in terms of their level of support need. As mentioned in section 2.4.1, prior to the Care Act 2014 (UK Gov 2014), support needs for people following assessments were described as mild, moderate, substantial and critical. The introduction of the Care Act 2014 (UK Gov, 2014) replaced these labels with a needs threshold, reported to be equivalent to the previous 'substantial' level. However, in discussions with the

Charity, it was felt that the needs of their service users was more demanding since this criterion was changed. They also highlighted that the role within the local authority that they relied on to receive referrals from had ceased to exist. This meant that families were now contacting them directly and the service had to manage this process due to differing levels of understanding of service user needs and what services could or could not provide. In addition to this the service felt that there was an increase in referrals for people with dementia than previously experienced. The organisation had had to manage the changing needs of clients.

As mentioned in chapter 2.5.1, access is pertinent to health inequalities and therefore this was further built into the design of the study (see chapter 4). The services across different sectors also highlighted issues regarding connections with other services such as transport. The latter was highlighted as a growing concern for services dependent on transport in order to ensure attendance and continued functioning. A charity had previously granted places to service users only to find there was no transport available or waiting lists for transport creating a barrier for some in terms of access. Such issue fed into the completion of the Health Inequalities Assessment Tool (HIAT), see appendix 4.

Spending a short time with services and their service users allowed me to visualise first hand, the types of disabilities to be considered when choosing the research tools. This process enabled me to ensure that the project was inclusive in its design. The population were labelled as a hard to reach group and by visiting the services I could ensure that the tools and measures chosen later did not inadvertently exclude prospective participants due to the nature

of their impairments or disabilities. To summarise, the early collaborative approach was advantageous to the design phase of the project. It enabled themes from both the systematic review and issues from frontline services to be built into the aims and objectives of the study. It was clear that anticipated challenges would fall into two types: those related to engagement with the day care services and those pertaining to the population group itself.

Firstly with regards to service engagement, services providing day care to the elderly do not have a record of research activity. Therefore, a lack of research expertise within the setting (Robson, 1993) limited the type of research methods that could be used realistically within the timescale for the project. A network of research active day centres to tap into or engage with did not exist. The research project and subsequent activity was expected to be a new entity for services to consider, not something that they would have experienced before. A review of services locally illustrated that many were in the midst of re-organisation and commissioning reviews, albeit at different stages of the process. Therefore, the approach to engage services had to be promoted in a way that both attracted services, whilst not appearing to be too burdensome.

Secondly, the older people attending the day service had a wide variety of impairments and disabilities therefore tools selected needed again to be easy to use and in a format that was accessible. High levels of sickness, frailty and appointments with healthcare services was cited in the literature and day care services as a barrier to attendance and participation. Initial discussions had also revealed a protectiveness by staff and volunteers of their service users due to their perceived vulnerability. The methods chosen would need to combat these issues in order for the study to be successful. The early

engagement of the services ensured perceived barriers could be negated early on. It was therefore decided to undertake some further wider preliminary work that could both gather further information about services and establish contacts with potential research sites.

### **4.3. Study Design – Day Care Survey**

In order to understand the current landscape more clearly locally a questionnaire was designed to gather further information (see Appendix 2). The following section provides information regarding the information collated. The survey was designed using an electronic web based design (Survey monkey, no date) and sent electronically to day care providers across the north west coast. In order to do this, the initial challenge was to identify the day care providers.

10 local authorities in the north of England were contacted for lists of day care centres of providers for older people. At the time the availability and quality of such information varied immensely between local authorities. Examples of the information provided by local authorities included general adult accredited providers, key websites for care homes that may provide day care, council websites with generic signposting information for older adults and one local authority advised to look on Google.

Although Healthwatch groups provide information on health and social services, this did not seem to extend to adult social care services with only 1 area providing a list of older people's services. A discrepancy also appeared to exist with some local authorities only providing information about their own provision, therefore services outsourced to other providers for this population group was not listed.

A website (Carehome, 2018), was highlighted by one area. The day centres listed were more predominantly for adults with learning disabilities, although some centres for older people were contacted this way also. This exercise demonstrated a wider challenge for families accessing services. Only those deemed to meet the threshold in many areas would then be given information about services. Others would receive information based on my experience above. A barrier to accessing support within the community has previously been reported as stemming from the complexities of establishing and sustaining a database of local resources. (Blickem et al, 2013).

A questionnaire was designed to understand more about the detailed aspects of current provision available. Information was collated about the following:

Funding of provision (S),

- Costs to clients (A),
- Places per day (A),
- Transport provided (A),
- Opening times (A),
- Types of activities (S),
- Care needs of clients (S)
- Inclusion criteria (A)
- Exclusion criteria (A)
- Access (referrals from) (A)

- Number of staff / volunteers (S)

The topics above were focused to capture two key unknowns about local day care provision. Those marked (S), were related to the service model for example how it was funded, what was on offer for those attending (activities), how it was provided (staff/volunteers) and what level of need it catered for. Those topics marked (A) were relevant to accessibility issues key to health inequalities. They were identified through the reflections following initial visits with centres, described in section 4.1.

The majority of the services were contacted over the telephone with the link to the electronic survey then sent to a specific email (usually the manager of the service). A small number asked for the questionnaire to be sent in the post or found it easier to answer the questions over the telephone. The questionnaire also had the advantage of providing an introduction regarding the project, facilitating further discussions about their services and the possibility of engaging with project. All services that responded indicated that they would be interested in being involved in the study and requested further information.

The following section provides an overview of the responses received from day care providers. Section 5.1, provides more detail regarding the process to select and recruit the sites for the study.

#### **4.4 Survey Results**

61 questionnaires were sent out with 40 local day services responding to the survey. The models of services available locally for older people with LTCs is discussed further in section 5.4.1. As expected the services were provided by using a combination of Paid staff and volunteers with a number of services



using Paid staff who managed a team of volunteers. 62% of services responding were classed as charities or Voluntary groups, with 38% of services responding classed as Paid staff services. The Paid staff services were used to support people either with a specific diagnosis such as dementia or substantial support need. Table 2, provides an overview of responses received.

It should be noted that the range of cost for Voluntary service has two figures for the higher end of the range. This is because a pilot service aimed at people with a higher level of need, who may benefit from an enhanced service had two top prices £41 and £60 for the day.

35% of the services were able to arrange transport for people attending the centre. The transport issue above highlighted issues for clients or family members accessing day care and in view of information gleaned when visiting services (described in section 4.1), the survey also supported wider issues in terms of criteria for accessing day care. For some services criteria included a geographical area. However there were criterion relating to diagnosis (for example dementia) with exclusions relating to severe mental health conditions or severe physical health, with dementia the most common criteria reported for exclusion. 25% of centres accepted self-referrals therefore reinforcing the need to understand of the issue reported about mismatch between families' understanding of clients' needs and what services are able to provide.

Figure 4, provides an overview of the types of activities provided by the services that responded to the survey.

#### **4.5 Defining Study Aims and Objectives**

The collaborative preliminary work undertaken with local day care services confirmed the variety of day care provision available for families. There is a complexity of arrangements and a variety of models (Gridley et al, 2012).

This study aims to recognise and understand that diversity in more detail and its impact on the lives of older people. Discussions with services and service users highlighted that the key aim of current day care provision is to improve overall wellbeing, whilst improving older people's independence and reducing any social isolation.

In addition, the systematic review found that half of studies only included the carers of older people and not the people attending day care. It was felt in view of national policy decisions, effort should be made to speak to those attending day care directly as opposed to their nominated representative.

**Figure 4: Range of Activities Provided at Day Centre**

Range of Activities provided at day centres	
	<ul style="list-style-type: none"> <li>• Live music</li> <li>• Bingo</li> <li>• TV</li> <li>• Board Games</li> <li>• Days out (sea side, garden centres and places of interest)</li> <li>• Horticulture</li> <li>• Crafts</li> <li>• Baking</li> <li>• Singing</li> <li>• Activities of daily living eg folding linen, washing up</li> <li>• Holistic Therapies</li> <li>• Chair Based Exercised</li> <li>• Reminiscence activities</li> <li>• Quizzes</li> <li>• Card Game</li> </ul>

**Table 2: Summary of survey responses received**

		<b>Paid Staff Service</b>	<b>Blended &amp; Voluntary Service</b>
<b>Cost per day</b>	Mean	£40.70	£25 - £34.80
	Range	£24 - 94	£3.70 - £41/£60
<b>Operational Number of Days</b>	Mean	5.4	2.5 days
	Range	4-7	1-5 days
<b>Operational Number of Hours</b>	Hours	7.75 hours	5 hours
	Range	7 – 8.5 hrs	4.5 – 5.5

Carers would also be included but the study priority was to include attendees of day care as opposed to solely their nominated representatives or carers.

This decision meant that participants would need to be able to understand any research tools or instruments. As collaborative discussions with service providers had also highlighted the recent changes to assessment criteria for older people, it was felt that the population group would be refined to those with moderate / substantial care needs. The choice of this population group derived from findings from the systematic review and initial discussions with providers. Therefore, both the population group and the type of impact to be measured were fed into the refined research question below:

**Research Question:**

The aim of this study is to explore models of day care for older people with moderate to substantial needs and examine its impact on their wellbeing, independence and social isolation and that of their carers.

The objectives were developed in a similar way as to the overall study aim above. Study objectives are highlighted below, along with an explanation of why the objective was selected as a focus for the study.

**Objective 1:**

To determine if the Paid staff models of day care provide better outcomes for older people with multiple long term conditions than Voluntary models.

The policy direction to reduce local authority spending whilst outsourcing many services to the third sector was a key point of interest for providers. Whilst the long term future of many day care services was unknown, outsourcing

statutory services to the third sector is an ongoing policy within the UK as cited in the White Paper, Caring for our future (HM Government, 2012). Therefore, the first objective was designed to understand in greater detail the types of services available and if this lead to different types of outcomes for the people accessing them.

**Objective 2:**

Examine the differences in service models in rural and urban areas.

The elderly population is increasing at a faster rate in rural areas than in urban areas. Differences in the age range of the population cause difficulties in service provision due to a lack of younger families in rural areas, resulting in volunteer shortages and lack of local care staff (DEFRA, 2013). Nearly half of all volunteers offer their services in the community care setting, in particular day care and social support. The types of volunteer roles undertaken differ between rural and urban areas (Hussein, and Manthorpe, 2012). The service provided by volunteers in these areas is of particular value to people such as those with multiple LTCs (Naylor, 2013) who rely heavily on the services. The logistics of accessing day care in rural areas impacts on the number of hours that care can be provided and barriers to regular attendance are exacerbated (Joseph Rowntree Foundation, 1995).

As discussed in section 2.5.1 access to services is a key factor leading to health inequalities. The systematic review revealed a lack of focus regarding the rural or urban setting therefore the second objective will examine this more closely to gain an understanding as to how the UK service model operates in rural and urban settings.

**Objective 3:**

Establish what aspect of day care provision attendees value.

The personalisation agenda within social care is a key policy within the UK, as a vehicle for the empowerment of service users (Dept of Health, 2010). The development of the personalisation agenda stems from the disability rights movement and the recognition of individual circumstances and needs rather than generic state imposed services (f, 2003). A criticism of the more traditional models of day care was that a 'one size fits all' approach was outdated (Age UK, 2011). The introduction of personal budgets would enable people to opt for the service they wanted, with day care more responsive to individual needs, therefore, needs led rather than service led (Clarke, 2001). With an evolving model of day care, the study will explore what aspect of the service older people value, to assess if the service is meeting their needs and expectations.

**Objective 4:**

Identify the drivers for people accessing Paid or Voluntary care

As discussed in relation to the third objective, the personalisation agenda within government policy enables people to decide which services they choose. Therefore, other preventative models of support for older people such as befriending services that take place within the home may be available to older people. In terms of such services relying on volunteers, the availability and types of roles required of volunteers differs across urban or rural settings (Hussein and Manthorpe, 2012). This objective will further explore the drivers and motivations for people and their families accessing day care services.

**Objective 5:**

Investigate the types of carers' needs met by day care provision

As outlined in the Chapter 3, the systematic review revealed that half of selected studies (16) included outcomes for carer respite. Seven of these studies, only focused on outcomes from the carers' perspective as opposed to the older people attending day care. There was also a focus solely on dementia, with ten of the 16 studies only discussing this condition. This research study was designed with wider LTCs in mind. Studies finding a positive impact for carers included services that provided support for carers (Droes et al, 2004 and Gitlin, 2006) and this aspect would be explored further using methods detailed below discussed in chapter 5.

The aims and objectives of the study were developed using both a theoretical and collaborative approach. Once the study questions were defined, the process of selecting wider methodology and research tools and techniques commenced. The following section illustrates that process in more detail.

**4.6 Chapter Summary**

This chapter provides details regarding the collaborative approach taken in the initial stages of project development. By engaging with services early through meetings and undertaking the survey, issues highlighted in the systematic review could be explored with providers. The information collated was used to generate the aims and objectives of the study. The following chapter provides details of the methodology chosen and specific measures selected for data collection.

## **5. Methodology**

### **5.1 Introduction**

The aim of this chapter is to provide an overview of the methodology used to address the research topic. The following chapter builds on previous chapters by providing the rationale for method selection, recruitment strategy, data collection and data analysis. The final part of the chapter (section 5.5) outlines the process of site selection and the initiation of the project with services. It includes reflections on the practical application of methods whilst working with services and clients. Figure 5, page 101 provides an overview of the project design illustrating qualitative and quantitative data collection from services, staff, volunteers, clients and carers.

### **5.2 Ethical Approval**

The study received ethical approval on 4<sup>th</sup> December, 2015 from the University of Liverpool Research Ethics Non-Invasive Sub-Committee (ref: RETH000947, see Appendix 3).

### **5.3 Mixed Methodology**

It was clear that the day care services were diverse and complex and any attempt to assess outcomes would need to consider and report this. A failure to recognise this diversity would leave any impact discovered, negative or positive unclear and difficult to replicate. In view of the objectives across provider types, methods would need to be compatible across the range of culture in Paid staff services, Blended and Voluntary services (Mountain et al 2017). As an exploratory study it would aim to avoid universalism by focussing



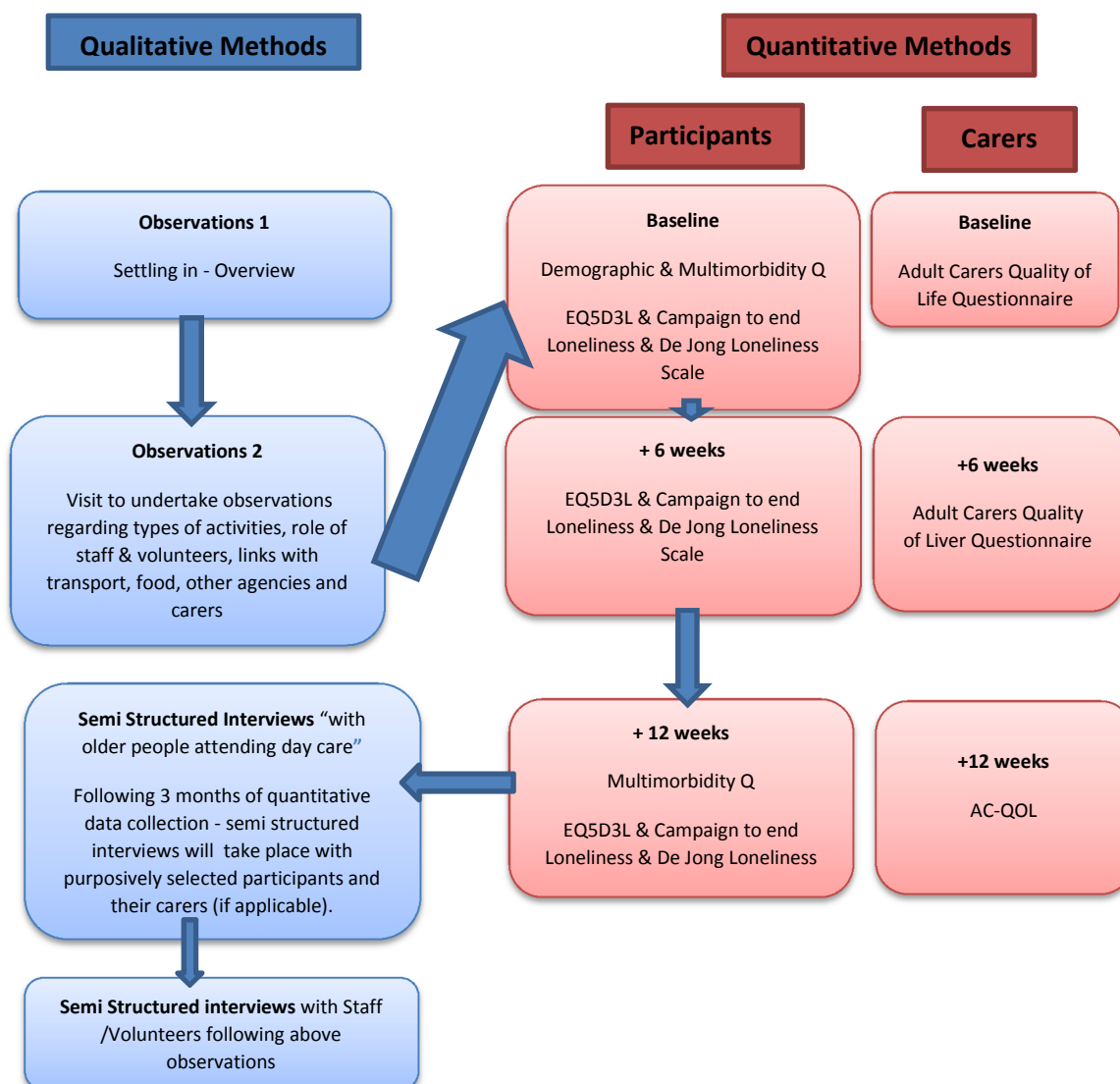
on the differences and similarities across the service types (Saks & Allsop 2013).

As the population group were anticipated to be experiencing moderate to high levels of illness, disability and isolation, any methods chosen had to be sensitive to this. Mixed methods approach is particularly useful for interventions when outcomes are difficult to identify (Farquhar, 2011). Whilst the project aim was to understand outcomes for people using day care services, a purely numerical, statistical method would have failed to recognise the variety within each environment. In mixed methods a number of measures can be utilised so that more detailed distinctions can be obtained from the results (Bryman, 2004), enabling more insight to be gleaned from the variety of questions relevant to the setting (O'Cathain, 2007). Therefore, mixed methodology was chosen to address the research questions.

Following meetings and discussions with service providers, it was clear the pressure on their time combined with the requirement to be sensitive to the vulnerability of the population group the methods had to recognise this. The research could not impinge on the service's ability to provide their activities and therefore the data collection would need to be undertaken by myself rather than delegate this to any staff or volunteers. To measure outcomes, data collection tools needed to be as simple and inclusive as possible. In order to address such key factors a combination of observations, quantitative measures and qualitative interviews were chosen.

The following section provides more information about the methods chosen. Figure 5, illustrates the data collection flow, demonstrating a longitudinal concurrent design whereby the quantitative and qualitative designs

**Figure 5 – Overview of Methods**



**Figure 6, illustrates the parameters for observations.**

**Figure 6 - Observation Parameters**

- How people arrive (numbers, with/without carers /community transport / independent transport);
- Type of support offered (supported for what and by whom / explore in relation to independence)
- types of activities (type/ numbers/ purpose / participation);
- Food, provision (type, provided by/ prepared by who)
- The aspect of day care that attendees value

mutually inform each other (Padgett, 2012). Section 5.5.1 provides detail regarding the rationale for site selection and the approach that took place.

### **5.3.1 Observations**

In order to understand the service model in more detail, observations were selected to complete this. Details of local findings can give a better perspective of wider understanding of what is happening in society (Savage 2006). Observations are a useful tool in settings where it is difficult to describe complex processes (Becker & Geer, 1957). It was felt that observations would work best when trying to compare and contrast the day service models across sectors. Interviews with service managers or questionnaires would not address the gaps in the research adequately. Observations would also reduce the workload of the services with the intensity of the data collection placed on the researcher as opposed to the service. This addressed pressures and capacity issues noted during the preliminary work.

Classic ethnography consists of full immersion in the setting and aims to gain in depth understanding and meaning of the social relations and practices observed. Whilst classic ethnography would provide useful data regarding the operation of day services, working across multiple sites and the need to assess outcomes for people using the services meant that a focused ethnographic approach was chosen. Focused ethnography is characterised by shorter time in the field, so part time ongoing multiple visits to settings as opposed to long term placements (Knoblauch, 2005). It was felt that this method would best enable the research objectives to be met, as opposed to classic ethnography only part addressing the objectives. In addition negotiating a long term placement with services under pressure would be

difficult. Focused ethnography method is advantageous when engaging with services not familiar with research, breaking down barriers with gatekeepers and navigating obstacles from those within the service. Where other traditional methods may struggle, focused ethnographic work including fieldwork and observations offer a non- threatening tool that allows the researcher to build up rapport with services and participants.

Focused observations were to take place in each setting to gain an overview of the types of activities provided and the role played by staff (Paid and volunteers). Observations would focus on the above but the method also offered flexibility so that any additional findings could be captured. In order to gain ethical consent for observations, the manager at participating day centres would introduce me at the start of the day to those attending the centre, explaining why I was there, what I was doing and to ensure that those being observed were comfortable with the project and the process.

Short term observations took the form of an initial visit to gain an overview of the day centre with the manager. Section 5.5.3 discusses how the observations progressed in each centre. Follow up visits were arranged to undertake further observations of particular activities, record field notes and to capture the uniqueness of the centre. This enabled a greater understanding of how the service worked with follow up visits arranged at a later date with the centre manager. Wherever possible, I sat with the participants attending the day centre and took part in activities from their point of view. Data generated from observations were then used to produce questions for staff in terms of clarifications. Interview questions with staff, volunteers, participants and carers were also developed using these observations.

### **5.3.2 Qualitative semi structured interviews with staff / volunteers.**

Qualitative interviews possess greater flexibility enabling the researcher to respond dependent on the direction in which the interviewee takes the conversation (Bryman, 2004). It was felt that semi structured interviews would enable questions to be developed following observations of the services. The informal structure would enable the member of staff or volunteer to respond in the manner best suited to them. The combination of observations and qualitative interviews enable a greater understanding of the service model, addressing the gaps in the current research literature. Section 5.5.3, discusses in more details barriers to consider when using this method in practice.

### **5.3.3 Quantitative Methods - Older People new to day care.**

In order to assess the impact of day care for the older people attending day care, quantitative measures were used to assess if attending day care has an impact on the older person's quality of life, loneliness and health outcomes. In order to properly assess outcomes for people as opposed to solely service satisfaction or experience, participants who were new to day care and met the inclusion criteria (see figure 7) were invited to take part in short questionnaires.

Day centre managers from participating day centres were given project information sheets (Appendix 4) and provided with participant information sheets (Appendix 5). Participants information sheets were distributed to the new participants who met the study criteria by the day centre manager. If prospective participants were interested they were invited to contact the researcher for further information.

The data was collected longitudinally at 3 interval points: baseline; 6 weeks and 12 weeks. Measures and instruments were selected depending on their appropriateness for the population group and inclusive format. Where possible previously validated questionnaires were selected. As an exploratory study the target sample size was set at a minimum of 60 people with a maximum of 100 people to enable data analysis to be meaningful. There was no data available regarding admissions or referrals to day care and the numbers were decided in view of methodological needs and extrapolated during discussions with service providers. The measures considered and selected are discussed in more detail below.

### **Quantitative Tools**

Participant and carer questionnaires are summarised in Table 3 along with the relevant timepoints for each measure. The process to select each questionnaire is discussed in the following sections below.

#### **i) Demographic Measure**

Demographic measures were collected for independent variables including sex, age, ethnic background, marital status, living arrangements, residential status, and socioeconomic status. The demographic measures were taken from recognised ONS indicators for older people. Collecting gender, age and ethnic background allows a better understanding of the types of people using the services. A criticism of the day care service model from the literature is that it is predominantly designed for women (Age UK, 2011), with men preferring more activity based services. Collecting this data enables valuable data generated that can enable issues around access pertaining to health inequalities to be explored in greater detail. Revealing any differences in

demographics between those attending the Paid, Blended or Voluntary services across urban or rural areas.

Similarly, marital status, living arrangements and residential status provide a greater understanding of those currently accessing day care services. There is discussion pertaining to the most appropriate measure of Socio economic status for the population of older people, with many indicators more appropriate to capture earlier generations (Grundy and Holt, 2013). Postcode and education attainment is regarded as best practice and/or professional status however, the latter option is detrimental for women of this generation who may not have worked. Therefore it was decided to use postcode combined with educational attainment.

## **ii) Quality of Life - EQ5D3L**

Physical, psychological and social outcomes of participants attending day care were to be measured using the EQ-5D-3L at baseline, 6 weeks and 12 weeks. The EQ-5D-3L is a tool widely used to measure health related quality of life, validated when used with populations of older people (Kaambwa et al, 2015). The questionnaire has 5 items and a visual analogue scale. It includes five domains: mobility; self-care; usual activities; pain/discomfort and anxiety/depression (Konerding et al, 2014). Each domain has three levels of impairment from eg no problems, some/moderate and extreme problems. It can be used for a wide range of health conditions, treatments and can be used face to face or by postal methods (Euroqol, 2017). In addition to its validation in older populations, there is a body of literature to support the validity and reliability in different language versions and conditions such as cancer,

diabetes, COPD and CV disease (Jansen et al, 2012, Kind et al 1998, Luo et al, 2005 and Herdman et al, 2011).

Prior to the selection of the EQ-5D-3L, other measures were also considered including Quality of Life in Alzheimers Disease [QOL- AD](Logsgon et al 2002), Older Persons Quality of Life PQOL-brief (Bowling, 2013) and SF36 (Ware and Sherbourne, 1992). Potential research tools were assessed in view of their appropriateness to the research question, use of plain English, brevity and validated in older population groups.

The QOL-AD, is a 13 item health status questionnaire measuring health and wellbeing in older people with Alzheimers Disease. There is a questionnaire for the participant and their carer that covers physical health, mental health, social and financial domains with four responses: poor, fair, good excellent.

The questionnaire had only been validated for use for people with dementia and whilst it had the potential to yield evidence within the older population, it was discarded for three reasons. Firstly, the carer's questionnaire whilst providing a perspective of the participants wellbeing from the carer's point of view would be an additional questionnaire for the carer to complete. Secondly, the questionnaire for the participant was dependent on the research being face to face and whilst the baseline data would be undertaken face to face, follow ups may be completed without the researcher either over the phone or sent in the post. Thirdly, the lack of validation for the tool in the older population meant that confidence in the findings may be reduced. Therefore the QOL-AD was discarded.



**Figure 7: Inclusion and Exclusion Criteria**

<b>Inclusion:</b>	65 years and older, more than 1 Long Term Condition, living at home, attending day care, able to give informed consent written or verbal, expected prognosis of at least 3 months
<b>Exclusion:</b>	Expected prognosis of less than 3 months, cognitive impairment such that unable to complete outcome measure unable to understand written / spoken English

**Table 3: Questionnaires and time points**

	Measure	Visit 1 baseline	Follow Up 1 (+6wks)	Follow Up 2 (+12wks)
<b>Participant</b>	<ul style="list-style-type: none"> <li>Participant Information Sheet (appendix 5)</li> <li>Consent (Appendix 6)</li> <li>Contact Details form (Appendix 7)</li> <li>Demographic Questionnaire (Appendix 8)</li> <li>Long Term Conditions Questionnaire (Appendix 9)</li> <li>Loneliness Scale (featuring End of Loneliness Campaign Measure and De Jong Giervald) (Appendix 10)</li> <li>EQ5D3L (Appendix 11)</li> </ul>	✓ ✓ ✓ ✓ ✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓
<b>Carer</b>	<ul style="list-style-type: none"> <li>Participant Information Sheet (C) (Appendix 12)</li> <li>Consent (Appendix 13)</li> <li>AcQOL (Appendix 14)</li> </ul>	✓ ✓ ✓	✓	✓

The OPQOL brief is a 13 item questionnaire, developed in conjunction with older people and their families. The engagement of service users complemented the overall project approach well. The questionnaire covers themes developed from older people and includes 5 responses: strongly agree, agree, neither agree or disagree, disagree; strongly disagree. However, it was felt that some domains were beyond the focus of the study and the EQ5D3L provided a shorter, more concise option.

In addition to the measures discussed above, the SF36 was also considered in view of the structured review of patient reported health instruments for health status and quality of life undertaken by Haywood et al, (2005). However, it felt that the questionnaire was too long, and the shorter version SF12 contained language, phraseology and questions that may be ambiguous when considering the needs of the population group.

Although specific instruments for older people were considered it was felt the generic instrument would better suit the needs of participants in its brevity, language and response options. It was felt that the administration of the questionnaire would fit with the data collection strategy and could be completed either face to face or independently. It was also validated for longitudinal data collection. It was suggested the measure facilitates identification of comorbid features that other specific disease or population instruments may miss (Haywood et al, 2005). It was felt that given the expected level of physical disability and sensory impairment of the population group, this measure met the criteria in terms of its brevity, simplicity, ease of use and previous validation with the population group.

### **iii) Loneliness**

Loneliness is a multi-dimensional concept (de Jong Gierveld, 2006), defined as a subjective perception of a lack of satisfying relationships (Andersson, 2010). In the older population it is associated with impaired quality of life (Jakobsson and Hallberg, 2005). Although often used interchangeably with the term social isolation, loneliness is perceived as distinct from this. Loneliness occurs when there is mismatch between the number and quality of desired social relationships (Pelman & Peplau, 1982).

As a key aim of day care is to increase social engagement and reduce loneliness, two instruments were selected to measure this. The De Jong Gierveld Loneliness Scale is commonly used when measuring loneliness (De Jong Gierveld, 2006). The second measure is a relatively new measure designed by the campaign to end loneliness in older people for services working with older people. Both measures are discussed in more detail below:

### **iv) De Jong Gierveld Loneliness Scale**

The De-Jong Gierveld Loneliness Scale is a 6 item measure. It does not use the term loneliness within its questions to avoid the associated stigma of the term loneliness (De Jong Gierveld, 2006). The UCLA measurement of loneliness was also considered (Hughes et al, 2004). This is a 3 question tool, developed with service providers and although it met the needs of the project in its brevity, it uses negative wording. Therefore, the questionnaire was discounted as it did not seem appropriate to use with the population group.

The De-Jong Gierveld Loneliness Scale, covers two types of loneliness: Social loneliness and emotional loneliness. Social Loneliness is connected to reduced social networks and therefore individual resources, whilst emotional

loneliness is pertaining to the absence of intimate relationships such as partner or parent (De Jong Gierveld, 2006). Its two dimensional structure of loneliness has been subjected to reliability and validity tests including a confirmatory factor analysis, and found to be valid and reliable in English and other languages (De Jong Gierveld, 2010).

A total score of 0 means that there is no evidence of loneliness with a score of 5 or 6 concluding intense loneliness. As the scale has been validated for this population group and commonly used to assess loneliness, the scale was to be used with older participants new to day care at baseline, 6 weeks and 12 weeks.

#### **v) Campaign to End Loneliness Scale**

Campaign to End Loneliness Scale is a short 3 point measure undergoing validation to capture loneliness in older people to be used by service providers working with older populations. The scale will be used at baseline, 6 weeks and 12 weeks. The measure was developed by the Campaign to End Loneliness for Older People Network, working with over fifty organisations in 2014. It is the result of a series of workshops during which four prototypes were drafted and voted for. Two proto types were tested across 18 organisations and 780 people alongside the De Jong Gierveld Loneliness Scale with the most accurate selected as the tool (Campaign to end loneliness, 2015).

It was decided that the measure would enable services working with the study to gain further understanding of measures available to illustrate the impact the service may be have. There is a growing expectation that services should

demonstrate their effectiveness during the commissioning cycle by moving towards more outcome based targets (Coulter et al 2013, HM Government, 2012, Addicot, 2013). Accompanying this expectation is concern from the Charitable and Voluntary sectors as to the suitability of target driven commissioning models such as payment by results and the capacity for smaller organisations to achieve this (Hadley & Joy, 2012 and Bhati and Henwood, 2013). It was felt introducing the services to the measure may be something that they could continue to use when the study ended.

However, the measure was discarded following experience with the first cohort of participants. Whilst only 3 questions, the formulation of the sentence was longer than the De Jong Giervald loneliness scale and caused confusion for participants. For example “I have enough people I feel comfortable asking for help at any time” was often dissected by participant with emphasis being placed on words such as “enough” and “any time”. The issue started to create a barrier with participants during the baseline and as follow up measures were required it was felt that it may be a risk to future data collection time points. Therefore the measure was withdrawn with the De Jong Loneliness scale used as the sole measure of loneliness.

#### **vi) Multimorbidity**

The systematic review revealed that few studies considered multi-morbidities when assessing outcomes for older people who attend day care. A data collection tool was required to collate this information from participants in order to address the gap of previous research. In order to prevent participants from only reporting their major condition as opposed to other LTCs, the Charleson Morbidity Index (CMI) (Charleson et al, 1987) was adapted to be used as a

prompt for participants reporting multimorbidities. Although the Charleson Morbidity Index is commonly used, it was felt when considering the population group, the terminology used more of a medical framework. As the concept of multimorbidities rather than detailed medical history was pertinent to the project, the categories from the CMI were adapted and produced on a shorter questionnaire. It was used as a prompt during the baseline appointment to better understand the types of conditions that applied to the participant.

#### **vii) Carers - Adult Carer Quality of Life Questionnaire (AcQoL) –**

For the purpose of the study, a carer was considered to be a relative or friend providing unpaid support to the older person for which they rely on for daily living (UK Government, 2014). If the older person attending day care has a carer, the participant was asked if they could be contacted and a questionnaire sent in the post. A carer providing paid support within home from a social care agency was not included in the study.

The AcQoL was developed by carers and professional collaboration and can be used for a one off assessment or across a time period. The tool is a 40 item measure, consisting of 8 domains of caring such as: Support for caring; Caring choice; Caring stress; money matters; personal growth; Sense of value and Ability to care (Joseph et al, 2012). As previously mentioned in chapter 3, half of the studies (16) in the systematic review included outcomes for carers. Studies that resulted in positive respite outcomes for carers were mainly of a qualitative design, therefore the inclusion of the quantitative questionnaire aimed to address this gap in previous studies.

An alternative questionnaire named the Carer Burden Inventory was used in a number of studies included in the systematic review, however it was felt that

the language was quite negative and the AcQoL was more appropriate for capturing all aspects of the carers' quality of life.

The AC-QoL consists of 40 questions covering 8 domains with 5 questions each. The domains are: Support for Caring; Caring Choice; Caring Stress; Money Matters; Personal Growth; Sense of Value; Ability to Care and Carer Satisfaction. The information below illustrates the results from the baseline data collection including

The questionnaire is scored as follows:

- Each question can be scored from 0 to 3, with each domain ranging from 0-15
- A total score ranges from between 0-120.
- The higher the score the more positive the quality of life.
- Total score of 0-40 indicates low reported quality of life
- Total score of 41-80 indicates a mid range reported quality of life
- Total score of 81-120 indicates a high reported quality of life
- A domain score of between 0-5 indicates low reported quality of life
- A domain score of between 6-10 indicates mid range reported quality of life
- 11+ domain score indicates a high reported quality of life.

#### **5.3.4 Participants (attendees at day care) and Carers Qualitative Interviews**

It was felt that qualitative methods would be appropriate to use with a selection of participants and carers to further examine the impact of day care on those using the services (consent forms see Appendix 15 and 16). Interviews would enable the participants and carers to discuss their experiences using their own words. Whilst an unstructured interview or forms such as a narrative interview (Reissman, CK 1997) may enable participants greater flexibility to present their experiences and how they portray them, it was felt that due to the burden of

illness this may be too challenging and put unnecessary pressure on participants. As the topic of the interview was more focused around their lives in relation to day care, semi structured interviews therefore appeared more appropriate. Prompts were used to guide the participant through the interview. As previously mentioned in section 3, the systematic review found two studies (Droes et al 2006 and Gitlin, 2006) that showed a positive impact for carers. Both compared a type of enhanced day care, providing support for the carer as well as the older person, with regular day care service. The involvement of the carer produced positive benefits and qualitative interviews with carers would enable further exploration of this in relation to the UK day care models.

## **5.4 Analysis**

Whilst using mixed methods, it is often the case that the various components are analysed separately with either quantitative or qualitative given different weighting (Padgett, 2012) when reporting outcomes. However, as data collection is longitudinal and complementary to each other through the various timepoints used for this study, an intertwining of analysis also takes place.

### **5.4.1 Quantitative Analysis**

SPSS was used for quantitative data management and analysis. Initially descriptive statistics were used to look for patterns by service and geographical type. Comparison standard hypothesis tests for paired data to assess changes over time and independent samples to assess between model differences were used. Baseline data were explored using the chi square test, t- test and one-way anova. Group mean differences for reported number of EQ5D3L problems and De Jong -Giervald loneliness scores were examined using one-way anova and repeated-measures anova for differences



in trend over time. Associations between service type and score changes during 12-week follow-up, were investigated using univariate and multivariate modelling.

#### **5.4.2 Qualitative Analysis**

Qualitative data was initially analysed using thematic analysis (Ritchie & Lewis, 2003), with analysis supported by the use of NVivo software. However, as data collection took place across multiple sites the analysis developed using constant comparative analysis, whereby data across sites is compared as data is collected and further data collection refined (Glaser, 1965). This is also referred to as recursive cycling (Killett et al, 2013). Therefore, observations were followed up with questions to staff and volunteers. Observations at one site could be compared with another for consistency and inconsistency.

As an exploratory study, the aim of this thesis is to open up the topic for wider debate. To ensure trustworthiness of data, processes were put in place during the analysis with regards credibility of data through triangulation, validation and reliability (Bryman, 2004). To ensure confirmation of data sources from participants that took part in the interviews (clients, carers, staff and volunteers), transcripts of the interviews were provided to ensure that they were a true reflection of the interview. There were no disagreements about the contents. Selection of transcripts were read by supervisors.

Triangulation is a process whereby data collected can be cross checked with other data sources (Guba and Lincoln, 1985). In ethnographic research it can reveal different perspectives on specific issues regarding the creation of knowledge and can bring more depth to observations in practice (Gustafsson,

2013). This process was used as part of the recursive analysis discussed in section 5.4.2.

## **5.5 Getting in and Getting On**

The next part provide detail of how sites were selected and accessed and will discuss the challenges and benefits of undertaking data collection utilising the tools above.

### **5.5.1 Site Selection**

As discussed in Chapter 3, following a survey undertaken with day care services a variety of models were identified. Figure 8 below gives an overview of the types of services providing day care that responding to the initial survey.

As illustrated in figure 8, services on the Blended and Voluntary end of the spectrum were managed by Charitable and Voluntary organisations., sometimes as stand alone community groups whilst others were part of a multi site Charity or wider regional or national franchise. The Paid staff day care services supported people with a higher level of need either with a specific diagnosis such as dementia or physical disability. Local authority services providing support for people with more moderate needs were less available. Another type of service model included day centres or activity centres for adults with learning disabilities. The focus of these centres was not older age but learning difficulties whereby people who had been with the service would remain into old age rather than relocating to a new type of older person's service.

Multiple day services were then selected following a two stage sequential site selection strategy (Sharp et al, 2012) with sites chosen using purposeful sampling in view of their population group (moderate / substantial care needs),

their sector (Paid/Voluntary), their level of deprivation (deprived/affluence) see Table 4 and their geographical position (rural / urban). This ensured that the choice of case was closely linked to the underlying theoretical framework of the study rather than an arbitrary selection (Ebbingham, 2005 in Saks and Allsop). Figure 9, gives an over of the services selected to take part in the study. For reasons of confidentiality, sites have been given pseudonyms.

As illustrated in figure 9, service provision for older people with moderate to substantial needs can be viewed across a spectrum, with Paid services at one end and Voluntary services at the other. A number of services were categorised as a Blended service whereby provision included Paid staff supported by volunteers. Services were also selected by their geographical position. A number of services on the right hand side of the diagram were based in small urban areas surrounded by large rural areas. Discussions with service leads indicated that those attending the services resided in both the market town and rural areas. Poppy Service is a targeted service, specifically for people living in a rural area.

Health inequalities underpin the project and the appropriateness of sites was assessed in view of their level of deprivation, utilising the index of multiple deprivation for the neighbourhood of the setting. The rank and decile for each setting are listed below. The level of neighbourhood deprivation

Section 5.5.2 site initiation, provides more detail of the strategy taken to approach sites and the negotiation that took place in order to get sites to come on board.

### **5.5.2 Site initiation**

Following the survey results (section 4.4), the settings highlighted in figure 9 were contacted to discuss potential participation in the study. In negotiation with day care services who expressed an interest in taking part in the study, it was agreed the service would be given results of the findings relating to their service. This was an example of research bargaining, referred to by Lumsden to give something back in return for access to the population group or service (in Lumsden 2012).

In order to project manage research across multiple sites it was planned to recruit three sites at a time, undertake observations, recruit participants and then move onto another group of three sites. Thus a rolling project with wave A, B and C (each wave containing 3-4 sites) was deemed logistically manageable. It was felt that each wave could be revisited for a short time later on the project, ensuring sites did not lose interest and prevent research lethargy.

As the project commenced sites were approached with this plan in mind. Early discussions with sites, revealed that site initiation with Blended services and Voluntary groups were expedited. Usually as the people I met with were managers of the service and decision makers, project commencement could quickly follow meetings and discussions.

Paid services, particularly statutory services were easier to locate through information sites, rather than through community knowledge, however services from this sector usually required further discussions with hierarchical structures within the organisation.

Figure 8: Models of Day Care Providers

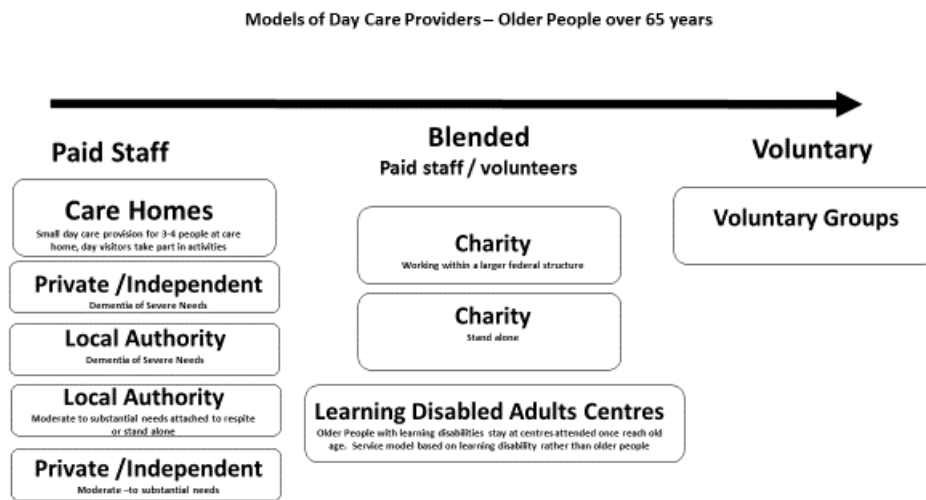
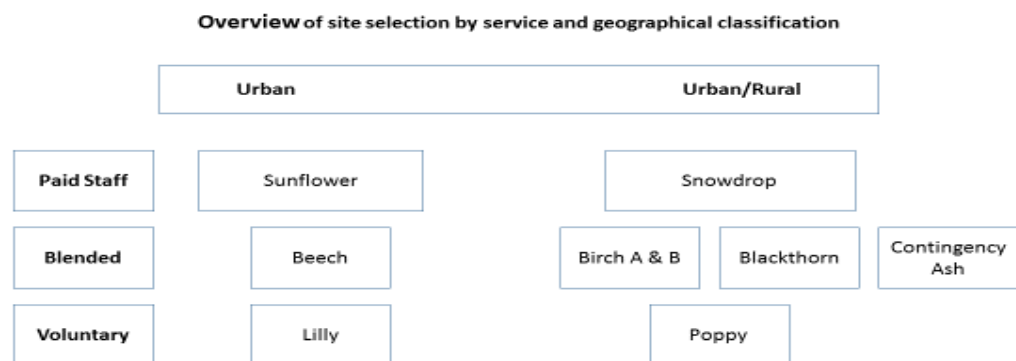


Figure 9: Overview of site selection by service and geographical classification



Therefore, the managers I met with could support the project but required authorisation from others that slowed the start up timescale with these services. Due to the speed of access granted, Lilly centre was selected as a pilot site.

This was to assess the appropriateness of the general project approach and research tools but also to ensure that the recruitment strategy was appropriate

in order to recruit new participants into the study. It was clear during the pilot phase that there was not a constant flow of referrals into the centre. After discussions with other participating sites, it was established that this was the case for all centres. I realised that by concentrating on only 3 sites at a time, the ability to recruit the appropriate number of new participants may not be possible.

Therefore in order to recruit more effectively, all settings were open to recruitment at the same time. This decision had a positive effective on recruitment figures and also the quality of data generated. It meant that a more comparative approach evolved with observations between sites, with findings from one site focussing observations with another.

### **5.5.3 Keeping in and keeping on**

As discussed in section 5.4.1 the climate in which day care services were operating was challenging. Therefore, sensitivity was used whilst maintaining relationships with sites. In the planning phase of the study, one service that managed three centres at the time expressed concern about the length of the study due to funding issues that they were aware of. The service stated that usually funding would not cause too many problems and any subsequent alterations to services would be minimal. However the coming year they had

**Table 4: Selected sites by Index of Multiple Deprivation**

	Index of Multiple Deprivation Rank	Index of Multiple Deprivation Decile
Sunflower	29	1
Snowdrop	1355	1
Beech	1331	1
Lilly	3994	2
Birch (A)	6304	2
Blackthorn	19098	6
Birch (B)	28845	9

*Poppy	1340	8
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\*Poppy centre is located in Wales and therefore the IMD for Wales has been used.  
Other sites are located in England.

been informed by commissioners that budgets may be cut completely and therefore were concerned that the service may close completely. In view of this on the horizon another Blended service was chosen for contingency in case this happened.

The contingency service was also expected to play a role in recruiting more rural participants as it was located close to large rural areas. However, it became clear that the contingency service was full to capacity and did not have space for new recruits in 5 of its 6 services. Again the two people recruited at the centre did not come from rural areas and the group were having difficulty attracting new members from outside the immediate area of the small community centre due to lack of transport available in surrounding areas.

The observations became a non-threatening way for me to introduce the research staff or volunteers delivering the service. The relationship was ongoing as opposed to a one off event (Denscombe, 2003). A number of the gatekeepers wanted to pass out information to clients who had been attending for quite some time rather than clients new to the service. This was to ensure the service was presented in a favourable light so that people with positive experiences would take part in the research. However, during observations the research aims could be appropriately described and services understood why people new to day care were to be the focus of the study. Explaining that the project wished to understand the issues that services faced and what needs the clients had. The motivations behind using people new to day care could be articulated so that services understood how the impact could be measured over the first 12 weeks.



It is understood the role that gatekeepers play and this may take the form of acting as a barrier to the research motivated by the aim of protecting patients from distress or perceived burden of research (Addington Hall, 2002). The observations also enabled the gatekeepers to assess the researcher and the project. The approach used allowed the services to be reassured that the burden of the research was minimal to the service and flexible in its processes. An added benefit of the observations was that they promoted the quantitative aspect of the project. Without the observations the method would have been more anonymous and it is felt less engaging for the services and participants. As new clients had usually met me during observations, when services handed out the information sheet there was more uptake to be involved rather than an anonymous questionnaire. This had a rolling affect that when I visited to provide information to prospective participants, gain consent and collect baseline data other prospective participants would meet me and again once information was handed out by the service the face of the research was known and uptake was good.

Overtime the combination of methods and ongoing visits meant that I was trusted with insights (Hammersley and Atkinson, 1983) in terms of challenges. Whereby initial observations were sometimes confused as a form of an inspection, visits to clients meant that overtime the follow up observations were more relaxed, informal and services at ease in my company rather than feeling observed. In some cases I was introduced as the services researcher. It is suggested that the researcher should aim to minimise the extent to which their presence may alter the situation, keeping the setting as natural as possible (Denscombe, 2003). However, services and clients seemed more

uncomfortable waiting on the side lines. Therefore on occasions if I was waiting for a prospective participant to finish an activity, I would accept the invitation to take part. This broke down barriers and built a rapport with clients. Supporting the notion that fieldwork can help the participant decide what interactions they wish to have with the researcher (Hammersely and Atkinson, 1983).

#### **5.5.4 Recruitment**

Participants new to day care were given an information sheet by the day centre manager that outlined the study with my contact details, for those interested to contact me. Participants were given the option of me visiting them at the day centre or in their own homes to discuss the project further. The majority opted for me to meet them at the day centre, with a small number choosing a home visit. At the initial meeting I talked through the information sheet using the principles of Informed Consent (Health Research Authority, 2017). It was made clear to participants if they chose not to take part it would not affect their experience at the day centre and if at a later date they no longer wished to take part, they could withdraw from the study without giving a reason. Participants were also given the opportunity to ask any questions before consenting to the study. Consent was given in the form of a signed consent form or verbal consent if the participant was unable to sign. The latter was recorded on a digital device and stored on a secure server.

Baseline data was collected within the first four weeks of attending the centre and collected at the same appointment following informed consent. The ethics permission included the ability to contact participants to remind them about follow up appointments which benefitted the follow up data collection. As

observations had been undertaken at the centre, when information sheets were given out by the day centre manager, the study was less anonymous with participants understanding that it was connected to me and able to put a face to the name. This continued as I returned to undertake interviews, new participants had a face to associate the study with. Therefore, the combination of method promoted the study where a purely questionnaire study may have failed.

At baseline if participants had a carer, permission was sought to contact them. Carers were then sent the questionnaires in the post. A small number of carers returned the questionnaires for reasons discussed later in chapter nine. The participants were informed about the qualitative interview and those that gave consent were contacted at the 12 week point. As with baseline the majority of interviews took place at the day centre rather than in participants own home. A small number of participants and their carers were interviewed together with most carers interviewed separately.

#### **5.5.5 Attrition**

21 participants were lost to attrition, (see chapter 7 for more information regarding this). Not all reasons were clear. It should be highlighted that due to issues with funding, one Paid service was outsourced from a local authority to a third sector organisation at the very end of the project. The Paid service had previously experienced reorganisation followed by a relocation in response to reduced budgets. Over the course of the study it became clear that further cuts to services would be taking place. The local authority would still fund care for people but no longer provide the service. Attrition was

minimal at this service until the service was given notice and then four people were lost to attrition.

At the other Paid service, attrition rates were noticeably higher than the first. The service felt that this was due to the high care needs of people attending. As people were unable to access support with moderate needs they were now accessing their services in some cases too late, discussed further in chapter 6. Therefore there was less time to support participants with carer breakdown unavoidable. In Blended and Voluntary services the reasons for attrition were often unknown. This could possibly be linked to the informality of the services and participants relationship with the service. Attendance rates would often fall due to illness rather than a stepped up level of care that would need to be negotiated with services.

#### **5.5.6 Safeguarding**

94 participants were recruited to the study and during that time there were two occasions whereby the distress protocol was used. Such examples are described briefly here to highlight the wider vulnerability some participant's may feel. In addition to the distress protocol (Appendix 20), a small number of participants asked for reassurance that I wasn't there to close the centre, whilst another clarified that the questionnaire was not associated with an assessment about living in their own home. All participant's remained in the study but illustrates the sensitivity around the population group moving between stages of independence and interdependence.

On one occasion demographic questions at baseline prompted visible emotion from a participant who became visibly upset. This was due to a recent relocation due to their partner's diagnosis with multiple conditions. Another

participant became distressed when answering the questions around loneliness. On both of these occasions, with the participant's permission information was passed to the centre manager so that appropriate referrals outside the day care service could be organised. The incidents were small in number but highlight the need for care and sensitivity when undertaking the research with this population group.

## **5.6 Chapter Summary**

This chapter has described the rationale for the methodology chosen and research tools selected. Methodology was selected to ensure gaps regarding service models in the research literature could be addressed. The project approach of inclusion ensured selected methods were accessible for participants, expected to have a wide range of disability and health issues. Site selection adhered to the theoretical underpinning of the project, with services chosen in relation to criteria that they met with regards to service provision, geographical area and deprivation levels.

This concludes the preliminary component of the thesis. The foundations of the thesis illustrating the background to the study, the current evidence from the literature, the approach taken to collaborate with services and the development of a methodology have set the scene. The following four chapters will present the findings from the research, organised from the three perspectives: day care services; clients attending day care and their carers.

## **6. Services**

### **6.1 Introduction**

This chapter will provide detail regarding the services that engaged with the data collection aspect of the study. The literature has highlighted that when day care services are the subject of research, little is provided in terms of service models so that findings can be replicated. Therefore, a key objective was not just to understand the impact of day care but to understand the service provided. In addition from a theoretical perspective, it provides understanding of the context related to the realities of the participant (Lincoln and Guba, 1985). In line with focused ethnography a short framework for observations was developed prior to visiting centres based on the components of day care understood at this point. They were: Referrals; Access; Transport; Food; Activities; Support; Carers. These initial focus points expanded and developed whilst attending the centres to include the following: Space; Service Integration; Group Dynamics; Connections to the Community; Evolving Service; Evolving Needs.

This chapter draws on data collected during multi-site observations and interviews with staff and volunteers. Data sources presented are field notes from observations undertaken at the centres and semi-structured interviews with staff. Section 6.10 provides a chapter summary.

### **6.2 Access**

The methods by which people access day care can be broken down into three parts. Firstly, how clients access the service in terms of securing a place at the

centre, secondly the strategies used by the service to support new starters and thirdly how they physically access the service. Therefore, access will now be discussed using these three components.

#### **6.2.1 Referral**

There was an expected clear difference between Paid staff services compared with Blended and Voluntary services. In order to access Paid services, clients had to meet a needs threshold via a social work needs assessment. Therefore, subsequent referrals for those who did meet the needs threshold were through social workers. Blended services and Voluntary services received self-referrals from older people or their families. On occasion there were also referrals due to health or social work professionals' recommendation.

This difference in the type of referral was pertinent to how services supported attendees. Paid staff services required a referral that included the detail from the needs assessment undertaken. This would include details on the client's LTCs and how it affected them day to day enabling services to plan appropriately to meet their needs practically. It would also include information personal to the attendee in terms of interests, likes and dislikes, occupational history and relationships all of which provided the service with discussion points.

Blended services had previously received more referrals from social care however stated that more recently this had reduced significantly and the majority of referrals were from individuals and their families. Two notes from observations at Beech service highlighted how this impacted the service provision at the centre.

1. *Day centre manager stated that when local authority services closed they expected to get more referrals from social care but this hadn't happened and there was a long gap without referrals. They investigated this and established that the post in social care that referred clients had been discontinued and therefore referrals by that method had stopped.*
2. *Day centre manager stated that the social work referral would be a lengthy document outlining the individual's needs from which staff would glean the relevant information required to support the client throughout the day. This caused issues for the service. On occasion a person prone to agitation had become difficult for the service who had felt this was made worse through the lack of information. The service had to develop their own information gathering form for new clients.*

#### ***Beech – fieldwork notes***

Other Blended services and Voluntary services cushioned the consequences of a change in the referrals processes by implementing their own procedures aimed at assessing the clients needs when with their service. Birch A&B, Blackthorn, Ash and Lilly Service undertook their own version of assessments over the phone. In addition to phone discussions with prospective clients or their families, the Poppy service also utilised home visits to meet with clients prior to their attendance.

#### **6.2.2. New Starter Strategies**

Centres across all service type enabled the new starters to have taster sessions. This was communicated as something to enable the client to decide if the service was the type of thing they wanted rather than commit



immediately. However, it was so that centre could assess if the service could manage the client's needs.

*We usually give them a day trial to make sure they like it, we like it and everybody is alright and can fit in and they're happy with that*

#### **Snowdrop – Paid staff interview**

*I think it's to see if the service is suitable for them whether its suitable for us, you know sometimes when they come in and they're like "mm its too noisy in here" you know they're not going to settle.*

#### **Beech Blended Service staff interview**

During observations one Paid service had discussed that community alternatives had to have been exhausted before clients could gain a place at the centre. Over the course of the study this criteria became more stringent and was extended to client's abilities whilst at the centre. This was contentious with staff but in effect clients were observed during their time at the centre and if it was felt they did not require their level of support they were referred elsewhere. This was despite a social worker assessing the client's needs as meeting the threshold and therefore requiring support.

*We give them six weeks and if it's a fit, it's a fit and if it's not we signpost and I assist the social workers and I'm saying do you know about this place, it's really good, it's a fraction of the price we are. They've got transport or they've got volunteers and they're a match for what they've got.*

*So when we do get in touch and we did that piece of work earlier on in the year and we looked at people's abilities and we*

*introduced people to alternatives that we thought people would be able to cope with. It wasn't just a case of shut the door and here's the info to the carer or who or er the person themselves*

### ***Interview Paid staff Sunflower Centre***

#### **6.2.3 Transport**

The majority of people attending the Paid services arrived via an adapted bus service. For Sunflower centre this was a bus that was dedicated to the centre with the driver staying on site and using the bus to take clients out on trips throughout the day. People would travel in with people attending the adjacent re-ablement centre. The Snowdrop centre utilised a community transport service provided in the area. Both Paid services had a small number of clients arriving with family members.

Two of the Blended centres (Beech and Blackthorn) had their own dedicated bus both funded directly from their own Charity. People at the centres also arrived on community transport and with families. A barrier to accessing the service was the lack of places available on the community transport. Consequently the staff mentioned they had places for people who could not attend due to lack of transport.

Neither of the Voluntary services had a dedicated bus service. Poppy service utilised a community transport service with a small number of people arriving with family. Those attending Lilly arrived using a mixture of community transport, family transport and taxis.

During the course of the project, community transport funding emerged as a further barrier to day care services. Two centres were affected when the

community transport service closed due to lack of funding. The service was later re-established but on a rationed service for the most economically viable routes. Prior to this event Beech Blended service had stated that they had people with places at the centre who could not start due to waiting list for community transport. The rationed community transport service was referred to during staff interviews.

*“There was a crisis with transport, nearly 18 months now I think it was.....more clients get taxis into day care now you know, they’ve had to do that because you know they can’t accommodate them in what areas they’re doing each day so that has affected some clients....And we’re still finding that those in the outlying areas (more rural areas) .... Those clients are being more isolated than others but we can’t get transport for them.....We have suggested maybe having one day a week were you would go to ‘em one of those outlying areas, take ‘em into town and then if they have any appointments, take them to the hospital or whatever erm bring ‘em to us as well but that has never happened”.*

#### **Staff Interview - Beech Blended Service**

#### **6.2.4 Transport and Long Term Conditions**

The type of transport available to clients did not just affect how the clients accessed the service but also how their long term conditions (LTC) were supported.

The Sunflower transport service did not just benefit clients in terms of their ability to access the centre but also to manage issues associated with their

long term conditions (LTCs). During observations this was demonstrated by two separate incidents.

*(1) Service coordinator phone call – a client's family had highlighted to the driver and staff that her leg was sore but thought she was okay to attend. On arrival it was communicated to staff who noticed that the rash had the appearance of cellulitis and would need treatment from the GP. The coordinator at the centre called the family to explain their thoughts. Discussion took place as to when they could get an appointment. The coordinator explained the group were going out on a trip and the bus would drop her home to save the family coming to collect her.*

*(2) Staff supported the driver on the morning run to act as an escort. One morning a call came in from the bus that a client had taken ill on the bus which was approaching the centre. An ambulance was called. The lady had a history of TIA (mini strokes) and faints. Following the incident the staff all met up to discuss and debrief. The driver was anxious as he had thought about stopping the bus where it was but staff reassured him he had acted accordingly. Staff displayed knowledge of the client's conditions and ill health that would occur as a consequence – .....[follow up note] It was interesting to observe that the lady was back in the centre after missing only one day despite hospital admission.*

The first incident demonstrates the flexibility the centre bus provided for clients throughout the day. The second incident demonstrated staff knowledge and

understanding of the client's medical conditions. The service bus provided a 'wrap around' service with the driver and staff escort supporting clients on their journey to and from the centre. In this instance, despite a hospital admission the client was in attendance after missing only one day, suggesting there may be some connection with support from staff providing confidence to return due to the knowledge and understanding of their needs.

In comparison the Snowdrop centre did not have a designated bus service. The service did rely on community transport. A referral for a lady with mental illness was received however she was unable to leave her flat when the bus arrived. The social worker asked the centre to keep sending the bus. It could be suggested that the bus driver or staff not being part of the service during the day may create an additional barrier for people who wanted to attend the centre.

Blended services discussed this issue around people taking ill whilst at the centre and the difficulty inflexible transport creates for staff and clients.

*"Because we did have an issue once when someone wasn't well and she came in a taxi and trying to get her home was a real concern because she wasn't bad enough to be going to hospital but she needed help just to her home and in the end we had to get her family out from work really to come and help with that so transport is a big problem"*

**Staff, Blended A & B**

For services without a designated bus service, the flexibility it provided and the additional support mechanisms for clients were not available. It was found

that the alternative type of transport used fell short of the support required by people with mobility and sensory loss problems at the centre.

*“social services used to have a fleet of well equipped mini buses with tail lifts on and they always had an escort driver as well and when the social worker rang up and referred the person the transport would automatically be sorted out by the social work buses but now they aren’t entitled anymore which has been a huge problem really.....*

*.....It is quite different because he can’t leave his bus unattended so the person needs to be ready and keen to come and to get them. I think they do try and get them door to door but if someone lives on the twelfth floor flat then they can’t do door to door and we have lost somebody through that, we tried very hard to get her to come but not having an escort for someone to come and bring her we did lose somebody”*

### **Staff Blended A&B Service**

The type of long terms conditions clients attending day care had created barriers to participants accessing transport to day care, in particular community transport. At the Lilly service community transport did not pick people up if they weren’t ready, due to other appointments. If the client was not ready within a small window of 10-15 minutes they would miss the day at day care.

*“Sometime because of their sight, they misread the clock or they are having a bad morning and are slower getting ready so aren’t*

*quite ready, dial a ride will just not wait, so then they miss the day, that's it because they have other places to go, so that's it "*

***Field work notes, Observation,***

***Volunteer, Lilly Centre Voluntary Service***

The centre proactively addressed this lack of flexibility by establishing an agreement with taxi drivers who could support clients more appropriately. During observations, the taxi driver brought two people and then mentioned that another was still in the shower, so he returned to collect him on his route for another small group.

*"So then I interviewed a few taxi people and made sure they had all the taxi permits and everything that I needed and they had to abide by my rules. No papping outside the house, they had to get out of the taxi, go the door then make sure the door was locked.....we've got the same five taxis for the same five years which means the people feel safe because they recognise the drivers. And erm this can go a long way to make them feel comfortable, because they know the drivers, the drivers make them feel good. They have to answer to me if anything is wrong and its worked very well for nearly six years and please god it carries on".*

***Volunteer Lilly Centre, Voluntary Service***

In contrast other services did utilise taxis however as there wasn't any agreement in place between taxi drivers and the service, a lack of consistency

with drivers created problems for people with LTCs and high incidence of illness.

*Yes there is a lady that comes in a taxi but she has been off a few weeks now and she is nervous about coming back she's actually in hospital she's not well and I just feel it's not that easy where she lives, there's steps involved as well and I can't...well I just think it depends on which taxi driver comes".*

**Staff – Birch A&B Blended  
service**

However, at the Lilly Voluntary service the change in provision had negated a barrier to service access, commonly experienced with people with multiple LTCs. Community Transport however in other areas did demonstrate levels of flexibility. For example, at the Poppy Voluntary centre, the community transport service was designated to the centre for the day. However, due to the distance that clients were travelling from, and the fact that not all lived within the area the bus serviced, client's relied on family or friends to take them to meet the bus.

The community transport service in the rural area demonstrated a flexibility that wasn't available in the urban environment due to demand and the rationing of services. The Poppy rural Voluntary service had access to the bus specifically for the centre, however the urban community transport service was also servicing other groups and therefore the same level of flexibility was not available, creating barriers to access in urban areas. However, it should be noted due to the distance that clients were travelling from in rural areas meant that clients relied on others to be able to travel to the location the bus serviced.



Another benefit of dedicated transport whether it be a dedicated bus service or dedicated taxi service was the monitoring function it creates for services. For example, difficulties being ready to attend day care, able to function leaving the home, for example remembering their bag or belongings and locking house, can be monitored by the transport service to raise with family members when issues are observed.

### **6.3 Monitoring Function**

The monitoring function regarding the transport service was also evident during the routine of the day service. This was noted during observations and mentioned by staff during interviews. It was felt that the advantage of those attending day care could be monitored for illness, dietary and fluid intake, interaction, medication and social issues. The staff also raised the cost benefit to be saved by people attending day care who would otherwise require medication prompts throughout the day or social care agencies preparing meals within the home. It was felt that the service filled a gap developing within the community due to rationing of social care services.

*“now that people don’t often seem to have social workers keeping an eye on them as much, I do think that they only see them in a crisis now and then they’re discharged and I do think the day service is a really good way of keeping an eye on people whose health is deteriorating and we know haven’t got family, erm you know we can pair them up with services or you know if we’re concerned I have rang GP services.....it is a way of keeping in touch with people or they are invisible really”*

**Staff, Birch A&B Blended Service**

*we can't administer any medication we can just say, so there's a couple of families today, they've said they've got their tablets in their bag so all I just say is, is it time to take your tablets?*

**Staff, Beech Blended service**

Day care triggered a more structured routine for the client. For some new starters there were challenges where services found that clients may struggle to interact, be slightly confused or tired. It was not always clear if clients were temporarily unwell or with higher needs than those that the service would usually cater for. The evidence below was related to a client who had started the service confused and staff were unsure if she met the service criteria. However, over the first few weeks it became clear that as she was getting up earlier she was having her medication earlier and it was felt this was responsible for her improved state.

*Now when she first come you could hardly understand her er she wasn't getting up for her daughter till nearly lunchtime and not wanting to come. Now this morning she was second person in and she was here before the bus. It's a big difference to her daughter.....she's got a long time to herself, she's got a respite from her but she knows her mum is getting up, wanting to come here and shes enjoying it.*

**Staff, Burntwood Blended Service**

Monitoring fluid intake resulted in new clients' lucidity. A client due to be relocated out of the area to be nearer family due to periods of confusion improved as volunteers noticed that the client was forgetting to drink. Her alertness improved and she was more engaged as the weeks went on.

*Client very subdued and withdrawn. Volunteer said she was upset she was going to have to leave area to be closer to family. Seemed very confused during conversations..... [1 month later].....client who was due to move, very engaged and bright at the centre, volunteer commented they noticed she wasn't drinking and were pleased to see the difference in her. They had presumed she was starting with dementia but she was much better now her hydration was being watched.....*

### **Fieldwork note, Lilly Voluntary Service**

The monitoring function extended to dietary requirements for clients unable to feed themselves or refusing to eat. Blended services would then refer families to services supporting people with higher needs.

*For instance if a client can't feed themselves, so you notice them struggling at lunchtime we then suggest to the family to move them on because we're only classed as like community... so we notice that a client starts to deteriorate or you know they're not interacting with other clients...So if there's deterioration in a client you know they're not eating well the family are informed, or social worker if they have no family..*

### **Staff, Beech Blended Service**

The role the service played in monitoring the safeguarding of this population group was evident during fieldwork as the following observation describes.

*Discussion between manager and driver that a client had money with her and they were pleased. The manager explained that the client had attended a few days without money to pay for the session*

*and had seemed quieter. The client had a relative with a history of substance misuse. The manager rang a relative to highlight the issue about the money and it was established the relative had been visiting the client and stealing money. The manager stated “if she wasn’t attending here, how would anyone know that was going on”?*

***Fieldwork, Blackthorn Service – Vulnerability/Safeguarding***

Personal dignity was a key concern for services where staff would discuss any issues about clients arriving not dressed or washed appropriately with families.

*Manager discussing with family that the client should have a warm coat on when being transported to the centre. Another family member was approached at the end of the session as the client had arrived on numerous occasions with clothes stained.*

***Fieldwork, Lilly Service, Carer Communication***

Incontinence issues not managed in Blended or Voluntary services could result in a client being referred on to a service supporting higher needs. One service worked with families to ensure any continence issues were checked out and addressed to enable people to continue to access the service.

*The staff member spoke to family due to ongoing continence issues and advised to speak to GP as family seemed to not know what support was available. The GP diagnosed a UTI and the continence issues stopped. Without this intervention the problems would have persisted.*

***Fieldwork, Blackthorn Blended Service, Carer  
Communication***

Client's perceived vulnerability was referred to by day care staff and volunteers. The service provided security and protection, a safe haven whilst in attendance. However volunteers at Lilly centre explained the population group could be targeted within the centre.

*"Activity worker, Paid via a Charity was observed talking to clients during the day and taking notes. A volunteer realised the person was taking addresses and phone numbers for clients. The manager regarded this as exploiting the clients who were being coerced into as having further sessions at home. The activity worker was asked to leave the service....."they come here for a break from that sort of thing at home and then even here it was happening".*

#### **Volunteer, Lilly Voluntary Service**

Continuing the safeguarding aspect of the service, checks for staff and volunteers had inadvertently created barriers for services. One service in particular had a history of using volunteers from a local college to support clients. However, there were cost implications for the checks required that resulted in the loss of this source of volunteers.

*"we had schools and colleges over the years but I think the CRB became a bit of an issue in that, I think it would cost quite a lot of money to have people CRBd who are under whatever the cut off age would be, I think it's 18. So it became too much of a cost....so if its costs us too much money to have the volunteers... it just was never resolved, and so they were not able to get people from the schools and colleges".*

## **6.4. Space**

A concept emerged during observations and was recorded in the fieldwork relating to the physical environment of the centres themselves. It was first noticed whilst observing the space available for services to undertake activities. Some had the use of multiple rooms, others only had access to one room that guided the types of activities that could take place. There was a variety of arrangements between the service and the facilities in which they were housed. For some the theme of integration was important however there were challenges arising from this. Table 5, highlights the working arrangements pertaining to the facilities used by day care.

### **6.4.1 Multi-Use Facilities**

The connection between the contractual nature of the day care and space and clients moving around once inside the building was highlighted during observations. At the start of the study, Blackthorn service was operating in the social club that was split across to rooms separated by a small staircase.

**Table 5: Working arrangements by day centre**

Service	Centre	Comments
Paid	Sunflower	Purpose built centre with adjoining areas linked to re-ablement service with inpatient beds. Day centre room within a suite of rooms (large multipurpose room, small consulting room and large therapies room with exercise equipment). Local authority owns the building and the service is also local authority.
	Snowdrop	Day care is in a suite of rooms (lounge – can be partitioned into lounge and activity area for crafts), kitchen, office and bathrooms accessible linked by a main corridor to a large hall used for community groups, a therapy room, a café and craft lounge. The centre is run by the independent company that also runs the day care. Lunch takes places in the main hall where the day care attendees eat with just over 50 people attending for a lunch club.
Blended	Beech	Day care take place in a lounge in a multi functional centre with a multipurpose room for exercises and a small room for hairdressing. Lunch takes place in a large hall, where day care attendees eat with people attending a lunch club. There is a kitchen specifically for the day centre and lunch club. The centre also has a drop in café for the wider community and a church. The centre that runs the day care manages the building
	Birch A&B	Day care takes place in a large multi-purpose room. Food is provided in a café/bistro. The facilities and food are not provided by the same Charity that provides the day care
	Blackthorn	Day care take places in two rooms in a social club with participants given access to the snooker room. The Charity that provides the day care does not own the facilities or provide and prepare the food.
	Ash (contingency)	Day care takes place in a room within a multi-use community centre, with other groups using the rooms on other days. The centre does not own the buildings it uses however the Charity does prepare and supply the meals that are delivered each day, ready made by the Charity.
Voluntary	Lilly	Day care takes place in a large hall within a community centre with a kitchen adjacent to the room. The day care volunteers prepare and serve the food. The service does not own the centre and pays rent to the local council.
	Poppy	Day care takes place in a small number of rooms adjacent to the church. The food is prepared on site by a Paid cook, supported by volunteers. There is a dining room, a small lounge area and an activity room.

The 20-25 clients navigated the stairs to move between activities and lunch or snacks. The mobility issues of the group meant that staff would stand at top and bottom of stairs to support clients who needed it. It was a short distance, however when the service relocated to an age friendly service the size of the room was smaller and was a long way from the bistro where clients would be served lunch.

There was discussion from the landlord to keep the group in the one room however the day care service felt that it was important for clients to move about and not feel hemmed into the one room. The result was that the long corridor the clients had to navigate was accessed by staff passes creating logistical problems supporting clients whilst not getting trapped in various segments of the accommodation. The accessible design in fact aimed at providing security and peace of mind to tenants did in fact create problems for those visiting for the day.

Another Blended service also had experience of this issue of sharing accommodation that caused issues between services with different levels of needs sharing the facilities.

*“There was the dementia day care service and we went there but that wasn’t ideal because there were a lot of people walking around and lots of locked doors and we had to be very careful about people going in and out”.*

**Staff, Birch A&B Centre**



The multi-use aspect of the building prevented the service from accepting more vulnerable clients who may try to leave the building. The fact that other groups used rooms made the availability of activities more restricted.

*it is quite open. Because we need it to be open because we have a coffee shop and we've got other things going on as well so we need it to be an open building. You know the men, they always liked the indoor bowling didn't they?, so if we had the bowling mat, we've talked about getting one but we never got round to it. If we could have a dedicated part of the building for day care. I went to another site and its great because it was just day care. It's going to sound lazy this now but if we could leave things in that room, set up as we like 'em and not have to clear it away. Yeah tidy boxes like you had a school (laughter). That would be a little wish list if we could do that because that was fantastic*

### **Staff Beech Blended Service**

A Paid service had previously operated from a stand-alone centre that was a ground floor centre with many rooms where clients could move about all day. During observations staff commented on the problems client had adjusting to the smaller "one room" service.

*"to go from being able to walk about freely and have the run of the place to being told to stay in one small room, it was unsettling for clients .....they were hemmed in and needed lots of time to adjust... they're getting used to it now.....Its brighter but smaller and claustrophobic".*

### **Staff, Sunflower Centre**

The other Paid service also commented on the lack of space available

*“I think the only thing we need is just a bigger building at the moment because we have that many people coming”*

#### **Staff, Snowdrop Centre**

##### **6.4.2 Together but separate**

The Sunflower centre was advertised as a multi-agency integrated service and the number of multipurpose rooms located close to the day centre lounge supported this claim. However, during observations it became clear that the multipurpose rooms were used by a Falls Clinic three days per week. Observations were made as it was presumed that day centre clients would be able to access this service. The Falls service provided half day sessions for people who had recently fallen or were at risk of falling. It consisted of an education session followed by individual discussions and activities with therapy staff, ending with group exercises. However, questions following observations revealed that only a small number of people who attended the day centre had ever had access to the service. The day centre manager could not directly refer to the service and people they felt would benefit from the service had to ask to be referred by their GP, leaving the referral to be initiated by the family. This seemed like a missed opportunity and exercises were not observed during the observation within day care and it was not referred to by staff or participants.

Birch A & B centres operated in a supported living housing association specifically for older people, running one day per week at each centre. However, in order for the Charity provider to be able to use the facilities it was

agreed that people living in the housing association could access the service for a lower fee. However, over time this caused financial issues with the service as the number of people attending from the housing association affected the amount of money generated by the service. In addition, the room the Birch A group used was small and restricted the types of activities the group could do. Despite a larger room available, the group were not given permission to use it. This affected the service development and the reason why the group relocated. So the service ran at the same centre Birch B two days per week as a consequence.

Blackthorn centre had a contract to use the facilities negotiated by the Charity. However, there were ongoing issues with the cost being too high for the service. As a social club, there were often functions that took place that then affected the rooms the service could use or the type of food that could be provided. Eventually the service relocated to a supported housing association. However, despite less cost to the Charity to rent the accommodation there were ongoing issues with the space that could be used (see movement section 6.8.4v) and the provision of food (see section 6.7).

#### **6.4.3 Integration**

Day care staff and volunteers discussed day care as providing interaction for people experiencing loneliness or facing social isolation to take part in the community. How services provided this community interaction varied across services.

*“So it’s to help them really to stay in society really and sometimes its to give carers a bit of break as well”.*

### ***Staff, Birch A&B Blended Service***

Clients at the Snowdrop centre spent the majority of time in the day care lounge, however they did move across to the main hall for food (see food section). A market stall or jumble sale took place in the lobby between the day centre accommodation and the main hall that clients accessed. A small number of clients chatted to people at the market stalls including a client with speech difficulties due to a stroke who used an alphabet board to communicate. A small number of the group also accessed activities such as dancing and crafts in the non-day care part of the building. Supported by a member of staff, they were able to mix with the other non-day care members of the group (see 6.8.5).

The Blackthorn centre prior to its relocation existed in a social club that was also used by other groups at the same time. One aspect of this was a group for parents and toddlers that ran for 45 minute sessions throughout the days that the day care operated. Parents accessed the group by walking through the day care group into an adjacent room. Therefore every 45 minutes a group of parents and toddlers would arrive and leave. During this time a number of toddlers would interact with clients which both parties enjoyed. Once the toddlers had moved on this became a source of conversation in the group either about their own children, grandchildren or the toddler group children that provided lots of stimulation for the group. Once the group moved to the new premises this ad hoc aspect of the service was lost and the group was observed to be much quieter.

Sunflower centre provided community interaction in the forms of trips and inviting groups into the centre. A community church provided sessions within the centre highlighting that by bringing the service to the centre it was removing the hurt and loss often experienced by this age group. Services in the community are designed around family, therefore people who are isolated and have experienced the loss of family members it reinforced that hurt and loss. A sister day service also visited the centre when entertainment was scheduled. Although the group responded positively to the entertainment there was little interaction between the members of the two groups.

At the Lilly centre the Paid activity worker, when not running activities also used pictures from her mobile to start discussions about what her family had been up to, initiating conversations between the small groups.

## **6.5. Multiple Long Term Conditions and Support**

This section develops the theme of space to look more closely at how facilities and services support clients with multiple LTCs. The accessibility of the buildings will be discussed in relation to various needs observed whilst attending the centres. In terms of accessing the building and moving around once inside, all Blended and services were designed or modernised to meet the needs of those who were disabled. However there was some variety in terms of other aspects of how disability was supported throughout the day.

### **6.5.1 Sensory Loss**

Visual or auditory loss was common amongst clients. Whilst space could be designed for physical limitations, it was stated that some of the rooms with hard floors and high ceilings proved difficult acoustically for those with hearing loss. It was noticed that the lack of assessments in Blended services meant

that the needs of those new to the service was unknown and only became clear during activities.

*The group were undertaking a cognitive game that consisted of letters on a flipchart. It became clear that a new client could not see the board and there was a rush to create a personal version so that they could participate*

### **Fieldwork, Birch A&B, Individualisation**

This was in comparison to clients who had had an assessment to attend Paid staff services who would have communication supports. For example, in Snowdrop Paid staff service a client unable to speak following a stroke used an alphabet board to participate fully in cognitive games. Clients registered blind had various voice activated technology to support them. This was not observed in other services, reflecting that those meeting the needs threshold were also able to access additional support in other forms to support them living in the community.

#### **6.5.2 Seating**

Paid services all had chairs with support either high backed chairs or chairs with full backs and arms to support people when getting up and down. This was the same for Beech Blended service and Poppy Voluntary service. The seating available at other centres did not have same levels of support. However, people attending did not have the same level of mobility need. At Lilly centre normal chairs without arms were available and those requiring more support were given V pillows that rested on the chair to give people more upper back support if required.

*“We don’t have comfortable arm chairs that’s probably the one thing we don’t have which would make a difference”*

### **Staff, Birch A & B Blended Service**

The above quote is from a member of staff who was comparing the new accommodation, differing from the previous centre where high backed chairs were in place. High back chairs were available in the accommodations lounge but were not available to the service that was operating in a different room.

### **6.5.3 Moving and Handling**

Paid services were observed using adaptations to help move people from chairs to wheelchairs, using moving and handling training. At Blended and Voluntary services clients were expected to be able to move independently with minimal support.

Moving to new locations could mean that adaptations previously available were no longer present, causing an impact on who could access the services.

*“we haven’t got an overhead hoist and I’m so used to that so we do have a physical need so we had to get used to that because we don’t have that. So some of them had to seek alternative services which is hard because if your legs don’t work and you can’t weight bear the most appropriate way for you....you know.....it can often be really frustrating if that’s the only thing from the bigger picture that is missing”.*

### **Staff, Sunflower Paid Service**

#### **6.5.4 Personal Care**

At Paid services accessible bathrooms were available for people who may have continence issues. Whilst the Snowdrop centre staff gave clients baths and supported personal care during the day, for Sunflower service despite having fully adaptable and accessible services they had been rationed in recent times.

*“There is a facility to do that here, it’s not that they don’t get it, it’s not encouraged. .... Showering, is done as a domiciliary care task and we’re not a domiciliary service, we’re day care.....to support them to maintain their independence yeah (shower/bath at home). If you did see someone compromised throughout the day or if say someone had an accident or someone came in and there’s been a disaster at home or say the daughter’s not been able to do the bath the night before. Then of course we will step in there”*

#### **Staff, Sunflower Paid Service**

The above quote illustrates components that were once part of the day care service only being available in periods of crisis with the responsibility of care being redirected to the individual or family with accessible facilities were provided at home. Hairdressers were available in some Blended and Voluntary services.

*I think it’s nice that we provide the hairdressers and the chiropodists once a month so you can see you can keep any eye on things*

#### **Staff Beech Blended Day Service**



*We also have a hairdressers here on a Friday where the clients can get their hair done, so that cuts down journeys to a hairdressers or have hairdressers come to the house, it means that they can have it done when they're in the centre. Which is another good thing*

**Volunteer, Lilly Voluntary Service**

**6.5.5 Evolving Service**

Those attending day care have a high incidence of illness and appointments that can make attending day care difficult. Evident during observations at Blackthorn where staff expected 22 people but 17 attended, one hospitalisation overnight, another had gone to stay with family and others were not feeling well enough to attend.

The service would obviously be affected with low attendance as attendees did not pay if they did not attend. However, at another Blended service there were plans to charge clients for their place as opposed to the session, therefore clients contributing to any lost revenue the service may have due to their LTC.

*“And one of the issues and I’m not sure but I think the cost is going to go up.... I don’t know how they’re going to resolve it but if people don’t come there, well people aren’t paying well then that can be a problem so how you say.....so how you then balance making something pay for itself with you know that and people are quite vulnerable and are often off sick for a few weeks and then maybe would have to pay”?*

**Staff, Birch A&B, Blended**

There was evidence that day care clients using the centre were not only older people. All services had clients who were under 65 years of age often with

multiple LTCs and physical disabilities and it was cited that lack of places for people under 65 meant services designed for older people were all that were available. There were also more clients with learning disabilities with closures to other services cited as the reason for this. Clients with substance misuse issues also attended before the age of 65. Services highlighted this as a change to their usual operational policy with closures to services resulting in staff and volunteers having to adapt to different types of needs. Some staffed services could draw on staff experience from other service such as learning disabilities. All services expected the rationing of services to result in more people under 65 accessing day care, altering the service dynamic over time.

#### **6.5.6 Dementia**

As mentioned in section 4.2 Project Design, during initial meetings with services it was mentioned that staff felt that there was an increase in people with dementia using the service. During the course of the study it was clear that there were people with dementia using the service but in many instances the term dementia was being used by staff, client and families alike to refer to memory problems or forgetfulness. It was not always clear if people had a diagnosis of dementia.

The presence of LTCs could confuse the situation with people not engaged fully due to reasons associated with aging or symptoms of their conditions. As mentioned in section 6.3, the lack of hydration could present as confusion as could particular medication. Due to the age of clients, it was a common assumption at some points that they may be developing dementia but services would consider other reasons in the early stages.

In fact two examples from my field notes below illustrate how my observations were on occasion clouded by the age of clients. On both occasions there was a different explanation for my observation rather than dementia, although this had been my initial assumption.

*2 new people in Blended service at baseline didn't know their addresses and reached into their pockets for cards. Realised during conversation that as the centre was based in supported housing, clients in the centre had relocated a few weeks before. Not cognition issues, just a coping mechanism during the settling in period*

**Note, reflective journal Blended Service**

*I arrived part way through an arm chair darts session, during which staff were manoeuvring a darts board around the room for clients to play. For some unable to take part due to physical impairment, staff threw for them or supported them to throw. One gentleman I presumed was disengaged possibly sleeping as was not taking part in throwing. It became clear after a few goes that he was in fact closing his eyes, concentrating and listening to the scores and adding them up for the staff.*

**Note, reflective journal Paid staff service**

The second quote exemplifies the ease at which ageist stereotypes can be applied in practice when observing this age group. However, despite other reasons apart from dementia during the above observations, services in the

Blended and Voluntary sector all commented on the increase in people with dementia using their service.

*Staff commented that there is another centre but its dementia specific and quite a few clients come from there. Staff felt that if they have an early stage dementia diagnosis, it is not suitable and the generic older people's service can accommodate their needs.*

#### **Fieldwork note, Blended service**

*A lady who was due to leave the service to attend a dementia specific service had reappeared at the day centre. Staff said she didn't settle at the new service despite it being dementia specific so the family had obtained an increased support package so that she can continue at their day centre five days per week. Staff commented as long as her behaviour doesn't upset other clients she will be fine. They find her happy and engaging but at the dementia services she was crying and trying to leave all day.*

#### **Fieldwork note Paid service**

There was a general consensus in Blended and Voluntary services that client's in the early stages of dementia were manageable in the centre. However, as the condition progressed there were difficulties this presented. This tended to be associated with the behavioural aspects of dementia, such as confused wandering that became difficult for staff to manage.

*one lady here and she was really confused and she wouldn't be coming in anymore, she had to, she's gone to a nursing home I think about 4 weeks ago and she's been here twice I think since*

*she's been there and she's was really confused and she wanted, she was heading for the door*

### ***Volunteer, Interview Poppy Voluntary Service***

*A new lady during the dancing kept dancing towards the door and trying to leave. It was quite demanding for staff and volunteers to distract her. Three doors led from the room and throughout the session she tried all three.*

### ***Fieldwork note, Ash Service***

The evidence above demonstrates the difficulty services may have accommodating clients with dementia. Issues alluded to in section 6.2 regarding how clients access or are referred to services are relevant here. As services are reliant on information from family as opposed to a formal assessment from social services, it is not always clear until clients start with the service that their needs cannot be met. Blended and Voluntary services operate in open facilities where clients who wish to wander are able to leave the building if not monitored by staff or volunteers, causing problems for the operation of services. Paid services operated in a secure environment where people could wander without leaving the premises. This issue highlights the impact that referral processes and available facilities or space have for managing LTCs, in particular in relation to dementia.

*Staff explained a gentleman had arrived with an advocate who then left. During the lunchtime the clients eat in a room with lunch club members. As lunch club members left the client left with them. Staff later informed he was known to wander but lack of referral information meant that staff were not aware until this happened.*

### ***Field note, Beech Blended Service***

*A client was moving around the centre, in and out of the office. When staff went for their lunch they took her out with them as she liked to walk. When in the centre they gave her tasks to do such as sorting laundry. The staff commented that this strategy had worked for quite some time with the lady with dementia but she had recently become aggressive with other clients at day care telling them to start working and shouting at them to not be lazy. As the behaviour had started affecting other clients the client would need to be referred on to another service.*

### ***Field note, Snowdrop Paid service***

This discussion will be continued from the perspective of clients in section 8.8.4.

## **6.6 Group Dynamic**

Services with more than one centre were able to place clients within the group that they thought they would benefit from the most.

*“so a man rang up the other day and his mum was widowed and lost her confidence, not going out so I suggested the smaller group ‘cos its quieter rather than one of the rowdier groups”.*

### ***Staff, Ash Blended Service – fieldnote individualisation***

During observations a member of staff commented on the difficulty of facilitating the group dynamic as “often the only thing they have in common with each other is the fact that they are old” (fieldnote, group cohesion).

*Well they get in this little group and they get to know who they like to sit with and a few of them are like naughty children, you know what I mean. And if someone is sat in their place, as they say their place but we always say there's no numbers and no names on seats but they always have this thing fixed in their mind, I'm sitting there that's my seat. But they can't do that,*

#### ***Volunteer interview, Lilly Voluntary Service***

However, in Blended services and the Poppy Voluntary services, the activities did not follow a repetitive format and were used as way to facilitate group dynamics. The dynamic of the group and abilities within the group directed the type of sessions delivered during the day.

*Yes and we try not to do the same activity all the time for that same reason because they would then choose the same activity and then it would be the same group., so we try and alter things all the time and just for variety as well. I think to keep us all, all interested as well*

#### ***Staff interview, Birch A&B Blended service***

*Staff explained that the service had been designed for more able clients and pointed to a neighbouring hall with an over sixties exercise class. However, more disabled clients had accessed the service which then directed the overall nature of the group and what could be organised in terms of activities.*

#### ***Field note, Birchwood Blended Services***

## **6.7. Food**

This section discusses the provision of food and food service in the centre and differences between service types. This section also discusses fieldwork observations that illustrate an additional provision of food within the community models of the Voluntary services.

### **6.7.1. Food Provision**

The provision of the food and sourcing of food was different when comparing Paid and Blended services with Voluntary services. The quote below illustrates the Lilly centre kept costs as low as possible and were members of a Fareshare scheme whereby unused food would be provided and redistributed in the community.

*“There was Fareshare, we pay Fareshare every month. It depends what you can get, some you can use, some you can’t use er it depends on their likes and dislikes and then er we do Fareshare, now were we get donations now at weekends, because we work weekends now giving food to them who can’t afford to buy food”.*

#### ***Volunteer at Lilly Voluntary Service***

A community development worker from two separate supermarkets also visited the centre to redistribute food close to sell-by date. The worker from one supermarket also started to volunteer at the centre to talk to people who were quieter or less involved in the groups taking place. Similarly at the other Voluntary service, the Poppy centre, food was sourced by the Paid chef in preparation for the session and cooked on site by the service itself.



At Blended services, two services The Birch A & B and Blackthorn food was not provided by the service but through the catering provider at the contracted accommodation.

### **6.7.2 Food Service**

There were clear differences between the Paid, Blended services in how interaction took place between staff /volunteers and the Voluntary services. For example, in Voluntary services, volunteers would serve food and then join the clients for a meal. The roles of those using the centre would often merge with clients supporting people to lay the table and later clear up. Apart from the Ash service, Blended services and Paid services, staff and the volunteers were not involved in the serving of the food. In the Beech service a Paid chef was supported by a small number of volunteers who only worked in the kitchen. It was only at Voluntary services that volunteers and clients ate together. The Paid services had rotated lunch breaks that they would take either whilst the clients were eating often or leaving the building altogether. The person remaining would stay to check people had the food they had requested and support those that had issues with cutting food. There was a clear boundary during the lunchtime between those Paid staff/volunteers in Paid and Blended service and the clients. Although in Ash service staff and volunteers did get involved in serving food, they did not eat with the clients and stayed separate.

The Birch A service that relocated to amalgamate with the Birch B service utilised the bistro provided by the supported living housing association. However, as the group grew it was felt that the group sitting in the bistro area was preventing residents from using the bistro and instead food was served in

the large room the service used for day care. Blackthorn relocating to its new supported living housing also experienced the housing association not allowing the group to use the bistro and this had to be negotiated at a high level.

The 'together but separate' theme continued throughout the provision of food for Paid and Blended services. At the Snowdrop Paid centre, clients joined around 50 people attending the luncheon club hall for food. However, they sat on a separate table to the luncheon club members away from the lunch club. This seemed a missed opportunity for integration with the wider community however, this seemed to be to enable those with fine motor skills problems who struggled with cutlery and needed more time to feed themselves to eat at their own pace without feeling rushed.

At the Sunflower centre those going on trips would often have lunch in a pub and those remaining in the centre would eat in a communal area in the rehabilitation part of the centre with other service users from that part of the building.

### **6.7.2. Food and LTC**

There were differences in how Voluntary services were able to accommodate LTC dietary preferences compared with Blended or Paid services. Voluntary services could provide an alternative one on one if required but usually the meals were designed to accommodate the whole group. Meals were blended for people if required. In Blended services Birch A&B and Blackthorn offered clients an alternative as staff providing food were not involved in the running

of day care. The Blackthorn service experienced issues with the alternative menu when relocating into a new building.

*And I think we were led to believe that it was like our other centres as where they have got an alternative everyday but there saying here “no you can’t be saying I want this I want that”, were considering it’s a café I think you should be able to have what you want really.*

### **Staff, Blackthorn Blended day service**

Therefore, the relationship between the provision of food and contracting arrangements again impacted on how LTCs could be supported during food provision.

#### **6.7.3 Food and the community**

In Voluntary services, the provision of food provided links with the community beyond those attending the day care. During fieldwork a volunteer from the Lilly service was observed delivering food to a neighbour of the centre, caring for a terminally ill relative. On another occasion a volunteer sat with the relative so that the carer could run a short errand. The Poppy service also took meals to older people in the community not attending the day centre at the end of the day.

The provision of food at the Lilly centre also extended to families who required support.

*It’s not just about ourselves, it’s about the community. Because this is a highly deprived area here not locally, nationally I know another man who has a wife trying to better their situation. He is an epileptic*

*and they have four children and I mean she works nights. So these type of people you're trying to help because they know you're trying to help themselves, they're trying to do a better life for their family and he comes here as a volunteer and also one of his children, he comes and volunteers when he's not at school. So this is it, what we give them, we get back in other ways. I don't know how it works, but it's funny. The more we give out, the more we seem to get.*

### **Volunteer Manager at Lilly Voluntary Service**

## **6.8 Activities**

There was common agreement across services that the purpose of activities undertaken in the centres was to support independence, facilitate engagement and stimulate clients who would otherwise be isolated. However, observations at the centres demonstrated that how this delivered varied across centres.

Analysis of field notes enabled the types of activities observed to be categorised pertaining to the type of involvement of clients, method of delivery and the type and purpose of activity. The types of activities observed ranged from individual or solitary activities, one to one activities, small group activities and large group activities. This section will now discuss the activities in further detail.

### **6.8.1 Individual or solitary activities**

It was interesting to observe that despite day care marketed as somewhere for clients to meet people and have company, in Blended and Voluntary services for there was small consistent group that undertook solitary activities such as reading or crafts. The solitary activities substituted large group activities that a small number of people wanted to opt out of. In some instance

this was facilitated by volunteers helping people choose an individual craft task but on many occasions it was people bring their own activity such as a book to read, a newspaper or knitting.

There was a recognition from Voluntary services as to how attending a larger group could be a difficult process for people who were experiencing recent crisis and isolation as the example below illustrates.

*Activity worker gave an example of a gentleman who had been attending a few months. He had relocated with his wife to be closer to family when his wife had died suddenly. With family working he had become isolated and lost any confidence to go out. Rather than take part in activities the aim for him was just to get out of the house to attend. However when first attending he would not engage and just sit and cry. "slowly slowly different ones have taken time to sit with him and he's still not joining into the groups but he sits and chats with different ones. So gently he's not crying anymore, he comes more days now as well".*

**Activity worker, Lilly Service**

Although individuals could take part in isolated tasks they also enabled unstructured one to one discussions and conversations to take place. Male clients were discussing newspapers, female clients discussing books. The example below highlights how the activity can be undertaken individually whilst still interacting as part of the wider group.

*A lady was sitting on her own knitting. A volunteer went over to chat to her. She had completed an item of clothing for a baby. The volunteer then took it to the manager to see and around other group*

*members. Later on another client joined her. The group had decided the clothing could be sold on the upcoming fundraising event stall to raise money for the club.*

***Field note, community contribution Lilly Voluntary Service***

Unstructured individual activities tend to require limited facilitation from staff or volunteers at Blended or Voluntary groups. Progressing to one to one activities, further support was required, as section 6.8.2 discusses.

**6.8.2 One to one activities**

At Blended and Voluntary services staff and volunteers were observed initiating conversation with clients. At the Sunflower service this tended to be isolated to the welcoming period at the start of the day. However, the Snowdrop service did facilitate conversation and staff were observed acting as the go between for two clients who were trying to hold a conversation as the fieldwork note shows below. This was quite common in downtime between activities, usually whilst staff were preparing drinks and snacks.

*A lady who was blind and quite deaf was holding a conversation with another lady who was very quietly spoken. The member of staff sat herself between the two and repeated what each other was saying. For the lady with hearing difficulties this consisted of the staff member having to shout quite loudly. The client would listen carefully and then chat back full of thick description related to the topic (a mill that the ladies both knew). Despite sensory difficulties both clients and those around them were having a lot of banter through these memories, with support from the staff member acting as a facilitator.*

### ***Fieldnote, communication, support Snowdrop centre***

Blended services and Voluntary services also facilitated conversation within the group. On occasions this may be a volunteer sitting with a new member of the group to get to know them and find commonalities with other members of the group. In addition to conversation, staff would also use sensory stimulation in the form of hand massage.

*And sometimes when the girls are doing a little bit of pampering and that might be just filing a man's nail as well and I encourage them just to put a bit of moisturiser on as well and rub their hand. You know, just some of the tactile contact, cos people don't have that, people don't have that.*

### ***Staff interview, Sunflower Paid service***

*Staff were monitoring a lady who was very quiet and pale who had recently been poorly. She was not engaging with the group activity. However when a staff member started doing one to one hand massages she lit up and was chatting at first to the staff member and then to other members of the group.*

### ***Field note, Snowdrop service, therapy***

A volunteer at Poppy Voluntary service described how she used hand massage to engage with a lady who was very withdrawn within the group due to LTC communication issues.

*But anyway, when I was massaging her hands, she started singing and I thought that was really nice wasn't it and it was a great help I think and there is a lady who comes here from the Red Cross and*

*she gives them a hand massage you know the back and shoulder and she is really good.*

### ***Volunteer Interview, Poppy Voluntary Service***

#### **6.8.3 Small group activities**

Activities in small groups of 3 or 4 and could be collaborative in the form of crafts or competitive in the form of cognitive games. The latter was often supported by a staff member or volunteer across all services. For some services there was a repetition of activity that clients expected as part of the structure of the day. Staff discussed the connotations for particular activities and also the challenge to providing individual choices in the current climate.

*There's a couple of them that like playing dominos and at first I was like, oh no you're not just playing dominos but it's getting them thinking, getting them looking and recognising what they have got with dominos isn't it.*

*We take one or two of them have carried on playing snooker and one of the men that we do take, it evens his dementia because he could be all confused and everything and he'd go there and play snooker and he knew what he was doing. It really did stimulate him*

### ***Interview Staff Blackthorn Blended Service***

The service lost the snooker component of the service due to a relocation to new premises as a consequence of cost. Previously, the leisure and social function room the group operated from meant that a small group of men would play snooker supported by a staff member. The loss of this component



created challenges to the service who tried to accommodate the client's individual preferences or expectation with what was practically possible in order to run an effective service. The above quote highlights the challenges relocating brought for some activities.

#### **6.8.4 Larger group activities**

It was observed that staff and volunteers leading group activities demonstrated skill to assess whether people wanted to engage or needed minimal support to engage or did not want to engage in particular activities. This developed over time with an understanding of individual needs due to LTCs. Activities throughout the day in all services rotated between large group activities and small group activities. Whilst individual solitary activities were less common in Paid services, the individualisation was promoted through client choice as illustrated below.

*There's no use banging the drum and saying we've got that idea, it's got to feel like people are in control of what they want. So you've got your traditional stuff like the bingo. Is it going to the Mecca like in the old days were you can win big money or is it prize bingo where you can win stuff here. And so do you like singing? You have to be more specific, do you mean singing joining in or do you mean a singer coming to entertain you? So we had a foundation then to build on.*

#### ***Interview Staff, Sunflower Paid centre***

Activities were booked in consultation with clients and staff felt this was empowering for people with LTCs.

*petting an animal, just having the sensation...we have a blind man who never in a million years would be able to touch an animal that isn't a cat or dog and scream with pleasure and all it took was someone to marry them up. I've seen her do that (staff member worked to understand client's preferences) so many times and you're making that person feel empowered enough to feel like, this activity has been arranged for me and how good a feeling will that be?*

### ***Interview Staff, Sunflower Paid centre***

The first quote above exemplifies the difference between activities designed to entertain people and those to engage people discussed further in section 6.8.5.

#### **i) Out and About**

As discussed earlier access to transport enabled Sunflower Paid staff service to go out regularly for outings. For other services such as Snowdrop, Blended services and Poppy service outings were more periodic for example, tied into Christmas or Spring time events.

*"We usually try and get them to the Xmas do and we go out and we were talking about taking them to .....the safari park this time, erm we try do one every year and get them out. And then we take some volunteers out that come with us".*

### ***Staff, Snowdrop Paid Service***

The above quote illustrates that as part of a wider organisation the Snowdrop service can access a team of volunteers from the wider older people's service.

Where there are issues for Blended services in addition to transport availability regarding supporting people out and about.

*“Also well some people really need one to one with some people, so personally I’m not a big fan of trips out. I think the canal trips fine but I don’t think it’s worth the risk and the transport...and this is their day out actually. If they didn’t have a day out from home coming here...and even with the canal trip over half of them don’t want to do it, so what do you do, cancel the day so half of them don’t come.*

**Staff - Birch A&B, Blended Service**

*“ so we booked a meal in a hotel and we could stay in the hotel, stay in the foyer and watch the world go by or we could go for a little walk. I feel like a lot of them have gone really frail to what they were and I feel like a big trip like that would be too much. Just thinking about the group”.*

**Staff – Blackthorn, Blended Service**

The Lilly centre had attempted outings and were often asked by prospective families about outings but due to experience were not able to provide this. A community bus was hired for an outing. However volunteers had to follow behind in their own cars to transport the large number of mobility aids such as three wheelers and walking frames. The outing was to a café in a park, however by the time everyone had got off the bus and then walked to the café, there was only a small amount of time still available to return to the bus and head back. The centre instead organise 6 weekly events within the centre. The “high tea” events have different themes for example, a trip to Blackpool,

Hawaiian, and volunteers and clients make crafts in preparation for the day for example head dresses for the Hawaiian day. The Community Development team at the local council support the group with materials for the day.

The section highlights the need for the service to support the needs of the clients pertaining to their disabilities. The next section discusses the role that the environment plays in supporting people during their time at the centre.

## **ii) Entertainment**

Services provided group entertainment in the form of speakers, music, singing, historical talks. The key aim of this type of activity was also to facilitate engagement. Therefore, an entertainer singing with a karaoke machine, supported by a staff member moved around the room with a microphone to encourage clients to sing along too.

*A number of clients would not sing over the microphone but were happy singing along quietly by themselves. All seemed to have particular songs that the staff member knew what order to put them on to make sure people were involved. One lady heard the introduction to her song and snatched the microphone off the support worker and marched to the front of the room, encouraging the rest of the group to join in on the chorus by pointing the microphone at them. Lots of cheering from the group. Various staff would also enter the room from other parts of the building upon hearing certain songs and take a turn on the microphone with clients clapping and singing along.*

***Fieldnote Sunflower Paid Service, Music***

Music was used as a way to promote group cohesion and breakdown barriers between staff, volunteers and clients. As one volunteer who led the singing commented during observations:

*“Eye contact is so important so you build that rapport and that intimacy with that person in the group and you get more from the group as it goes on”*

***Field Note, Volunteer Comments Ash Service,***

*The volunteer led the singing over the microphone that started with slower songs leading on to upbeat music, dancing as she did so. Individual clients joined her dancing in a group, all with mobility aids. Two married clients also danced to a jive and then separated helping the more frail clients get to their feet and join the dancing.*

***Field note, observations music Ash Blended Service  
cohesion***

**iii) Wider Social interaction**

Services, whilst providing interaction within the centre discussed the challenges of providing wider community involvement or social interaction. For example, when discussing a bowling activity in the community that clients wanted to take part in, the group found that they were the only people attending the bowling alley at that time. So a change of scene was provided however, further interaction was absent.

*You want the atmosphere you want fun and jumping up and down, getting strikes. I think real life is lots of people and in an environment, swapping and saying where do you live and all that?*

### ***Interview Staff, Sunflower Paid Service***

Opportunities were created instead by bringing groups to the centre. For example, the services' sister service joined the group for a singing session. Bringing new faces to the group for a period of just over an hour. As mentioned earlier, a local church also brought a weekly session into the group with a pastoral wellbeing theme, talks, singing and activities around the one theme.

#### **iv) Exercises**

All services apart from Sunflower Paid service provided the opportunity for people to take part in exercise activities. However, there was a difference between the exercises taking place in the Snowdrop Paid centre when compared with Blended and Voluntary services. In the latter group interaction was encouraged in the chair- based exercise, either hitting balloons to each other, passing balls about the group. Other tasks such as stretch bands and exercise manoeuvres facilitated banter and lots of joking between group members.

People taking part at the Blended and Voluntary services were able to do more than expected due to the support given and confidence gained throughout the session. However, it should be remembered that people at the Blended and Voluntary service, overall had less mobility issues than those at Paid services. At Blackthorn day service the clients were encouraged to stand behind chairs and lift their knee stepping while the leader explained that those who were living in adaptable flats and not needing to use stairs may lose muscle that could leave them vulnerable to falls later.

The Snowdrop Paid staff service did undertake chair-based exercises. However, these were observed to be more gentle with no interaction with equipment between group members.

#### **v) Movement**

Day care services have the potential to support people's mobility. There were differences between the sectors in how this was supported. In Paid services people's mobility was more severe and limited. As people ate in a separate part of the building they were supported to move to that part of the building by staff. Participants also moved into a larger room for singing activities (see section, 6.8.4 ii), however exercises for other opportunities for movement did not take place.

Snowdrop Paid staff service, also enabled people to move around within the day care environment and the wider older persons venue. Chair-based exercises were led by staff (see section 6.8.4.iv, regarding exercises). Ignoring exercise sessions for the moment, across all services there were opportunities to move about especially to eat food. However this was more restricted in the Voluntary services and also Beech and Ash Blended services. People did move around but the distance was much less due to the size of the space utilised by the service.

In Birch A&B and Blackthorn service in addition to moving around the centre the Charity received funding to initiate a step challenge supported by the public health team at the local authority. This involved clients being given a pedometer to count their weekly steps for a period of twelve weeks with the aim to increase their activity over that time. The activity took a large amount of time from the Paid leader each week to address issues with the pedometer

and to record the steps. 33 older people across the Charity took part in the project. Baseline data revealed levels of low activity outside the group but also during group activities that staff had not realised before taking part in this project.

*“I think a few people were able to take it on board but if you use, certainly what it has done it has made me very aware that people have to move around so when...I do, well yes we do do more now because of that”.*

#### **Staff – Birch A&B Blended service**

Opportunities to move during the sessions were increased. This included opportunities for participants to have supported walking during the day in the centre gardens. Frail and isolated members reacted positively to this and mentioned that the lack of confidence and fear of falling prevented them from moving more when at home. Family members mentioned the activity gave them something to “remember” and think about doing when not at the session. A client commented that they love to go outside more but are scared of falling so the team leader built a short walk around the garden into the sessions at Birch A&B. At Blackthorn the new accommodation was located next to a river, so short supported walks alongside the river commenced after lunch for those who wanted to.

#### **6.8.5 Community Engagement**

In addition to the activities that took place at the centres that were group led, group activities with a community theme evident in the rural Voluntary service. A local artist attended the centre. In comparison to the art projects observed in the Blended services there was a central theme of explaining components



of the project such as colour, form, shading with each week another aspect being the focus of the session. Blended services' discussion was around the construction of the craft item and choices in materials which differed in the Voluntary centre. Here during observations, a central theme of group discussions was the recent unveiling of a textile banner. The group had contributed to the banner by focusing on an item during their sessions which was then taken away and added to the banner. The viewing of the banner stimulated conversation between the group and the artist explained the aspects of the banner produced by the toddler group and the women's group. Contributory effort and linking to the community was evident during this observation.

Although not a group effort, other contributory effort at the other Voluntary centre was also observed providing links to the wider community. The small group of clients knitted rather than take part in exercise sessions. As discussed earlier, the finished products stimulated wider group discussion with the product being shown around the centre. The item of clothing was then used in fundraising activities to raise money for the centre. Other clients supported by the activity worker made craft items that were used as table decorations and to decorate the hall during the six weekly themed events. A regular occurrence at the centre included clients arriving with items for donation, to support fundraising activities. Clothes could be used in fundraising or kept at the centre for clients who may need them. Ornaments, books and toys would also be donated for stalls throughout the year and a small number of clients brought in vegetables from their gardens for clients to buy, the money raised contributing to the centre.

The community embedded approach and role clients played in this was only observed in Voluntary centres as opposed to Blended and statutory. There was fundraising in Paid services but through financial donation such as raffle tickets for a prize or a lottery. There was no co-production or community contribution observed.

#### **6.8.6 Culture**

Section 6.8.6 demonstrates the similarities observed regarding community engagement and co-production in both of the Voluntary services. However there were two observable differences between the Voluntary service in the urban area (Lilly) and rural area (Poppy). The volunteers and clients conversed using the Welsh language. The cook could speak some Welsh and time was spent with volunteers and clients helping her to develop her Welsh language skills.

As previously mentioned, the Poppy service operated from a church hall connected to the chapel. In addition to the use of the Welsh language some clients used the chapel during the day. Clients of any faith could access the service. However, in addition to the community co-production observed in section 6.8.6, there was also the common use of the Welsh language. This is explored further in chapter 8 from the client's perspective.

The Sunflower Paid staff service opened seven days per week and as mentioned in section 6.4.3, a community church visited the centre every Sunday. This is discussed from the perspective of the clients in section 8.7.4

## **6.9 Carers**

### **6.9.1 Respite**

The respite function of day care is recognised in the literature and policy. However, the respite function was mainly alluded to in the Paid services. The Sunflower service had the benefit of access to a local authority central IT system whereby information between social services and the centre could be shared.

*Day centre manager had taken a call from a relative. An assessment had been done, they had chosen the centre but had not had communication when to commence with the service. Relative concerned for the client's spouse. Coordinator directed to highlight as carer breakdown on system and went onto explain the advantage of sharing the system so that concerns could be reported quickly.*

#### **Field Note, Sunflower Paid Service**

The service was introduced as a service to benefit families requiring respite.

*"It's a seven day service that runs from 8:30 'til 4pm so the beauty of that is that if carers want a real good period of respite, they can drop them off at 8:30 and pick them up at 4"*

#### **Staff, Sunflower Paid Service**

However, the service acknowledged that budget pressures meant that respite as a service was rationed too

*“like respite....but even that is becoming smaller and smaller and that is because there just isn’t the same pot of funding that we used to get before”.*

*“Even with respite for carers we have to really examine erm who comes through the doors. Unfortunately the people who are feeling isolated or carers who just need a break for a few hours unfortunately don’t fit into that category”.*

#### **Staff, Sunflower Paid Service**

As part of a wider older people’s service a respite function could also be provided for families for shorter period rather than the whole day. The coffee shop run by volunteers and the day care centre also acted as a sitting service for those that required someone to watch their family member.

*“they come to us for the day just to give the family a break erm to make sure they’re safe knowing they’re in a safe environment. Sometimes we offer them where we can drop them off if they’re going or they’ve got appointment so they know they’re safe”.*

#### **Staff, Snowdrop Paid Service**

##### **6.9.2 Older people as carers**

As the respite function is referred to frequently in the literature, the project was designed to involve the carers in understanding the impact of day care. However, there was an emerging theme discovered during observations in that for Blended and Voluntary services people who were carers attended groups and there was a small number of people who attended with their carer. At first

it appeared to relate solely to the Voluntary services, however during the study it became clear that this was also present in Blended services.

At each of the Lilly and Poppy centres there were people attending with their partner or their daughter or son, plus participants acting as carers for their child. This was the same at Birch A&B with a married couple attending and another lady using the day care to get a break from her caring role for her husband with a terminal illness. At Ash a married couple also attended together. Therefore, rather than attending to give their carers a break they attended to get a break from other caring duties. Although a small minority, it was an observation in contrast the models in the literature that view the attendance of the client giving respite to the family member.

Whilst carers or partners attending was not discovered at Paid services, there was a member attending the Sunflower service who had previously been a carer for a person using the local authority sister dementia service but as they had suffered a stroke now attended the Sunflower service.

### **6.9.3 Aging together**

In addition to this it was observed that an additional pressure on carers was the multiple impact of multiple aging parents. An observation at Blackthorn centre included the son of a client who was managing the transfer of the father into long term nursing care. The mother attended the day care and was unaware her partner would be unable to return home. The centre manager was spending time with the son advising processes regarding support from

social care for the mother, as prior to the father's admission in hospital they had a mutual reciprocal caring role for each other.

In the Snowdrop Paid service a participant of the study had a wife in a nursing home. He had moved in with the son however left the study when he too was placed in a nursing home. This aspect of aging together but requiring support together does not appear to be acknowledged in the current literature.

### **6.10 Summary**

To summarise people attending Paid staff services benefited from resources, trained staff, advantageous staff to client ratios and access to wider services that support their LTCs. Transport, devices, equipment, furniture, bathroom facilities and accessible accommodation was available to enable services to provide support to people with LTCs. However, services provided by Blended and Voluntary services demonstrated service delivery that enabled more integration, connections to the community and a flexibility of service that facilitated empowerment of individuals using the service.

The following chapter will present the findings from the longitudinal data collection. There is little understanding currently whether there are differences in outcomes for clients attending the day services by service type or geographical area. Chapter seven will explore outcomes for the clients attending the day care service.

## **7. Client Quantitative Findings**

### **7.1 Introduction**

This chapter reports the findings from the quantitative element of the study. 94 clients who attended day care were recruited in this aspect of the study. The chapter will firstly address the follow up data and missing data analysis. Data regarding day care service users is not routinely available and outcomes for users are not known. Quantitative data collection was used to address this gap in research. Demographic data was collected from new clients at baseline in order to assess whether there was a difference in the characteristics of client's attending different services or at different geographical areas. This would illuminate any health inequalities in terms of access to services. Follow up data was collected at 6 weeks and 12 weeks in order to assess outcomes with regards to health and wellbeing and loneliness. Baseline data is provided to demonstrate the similarities and differences between people accessing the day care service type and geographical area.

Univariate analysis was conducted in order to describe differences in the baseline characteristics of the groups of clients using a particular type of day care service reported in Table 7 (paid, blended, voluntary) and those service-users living in urban or rural locations reported in Table 11. The significance of association between baseline attributes/outcome scores and membership of service-type and location groups was tested by the chi-square test for categorical variables and the t-test/one-way ANOVA for continuous measures. Section 7.2 outlines the results of the analysis, presenting differences and similarities of baseline characteristics by service type using chi square for

categorical variables and T test and one way anova for continuous variables. Section 7.3 outlines the results of the analysis by geographical location, reporting differences and similarities of baseline characteristics of clients using services in urban and rural areas.

Results from the EQ5D3L and De Jong Loneliness score characteristics report the results of the chi square for categorical variables and T test and one way anova for continuous data in Sections 7.4 and Sections 7.5. Section 7.6 provides the results of the differences in mean scores between the client groups at each time point (baseline, 6 weeks, 12 weeks), investigated using the t-test or a one-way ANOVA. Repeated-measures two-way analysis of variance was used to test for between-group differences in changing scores over time. Univariate logistic models were run in order to estimate the effect of type and location of service on the likelihood of 'any improvement' in outcome (a reduction in loneliness score, decrease in number of reported EQ5 problems, increase in VAS global health rating) from baseline to final follow-up. Odds Ratios, 95% confidence intervals and associated p-values are reported.

### **7.1 Complete and Missing Data**

94 participants attending day care were recruited into the study. Table 6 illustrates that follow up data was available for 73 people. 21 people were lost to follow up. In order to check any bias within the sample, those who were lost to follow up were examined in more detail. Figure 10 illustrates that the most common reason for leaving the study was due to illness. 24% left the service for unknown reasons as this data was not recorded by the service.



44 % of those who were lost to follow up were from paid staff services, 24% Blended services and 25% were from Voluntary services. As discussed in section 5.5.5, 4 participants were lost to the study due to a sudden loss of a staffed service. These participants did not leave the service or study through choice but more operational issues with the service. By removing the 4 participants from the missing data analysis reveals 33% of those lost to follow up were from staffed services, 28.5% from Blended services and 38% were from Voluntary services. The clients that moved to nursing homes (8% of sample) were from the snow drop Paid staff service.

The following section reports the findings from the data collected from 94 participants at baseline. The results will be presented initially by service type, section 7.2 (Paid staff, Blended and Voluntary) and geographical area section 7.3 (urban and rural).

## **7.2 Baseline Characteristics by Service Type**

Table 7, below provides the results of univariate analysis, conducted in order to describe differences in the baseline characteristics of the groups of clients using a particular type of day care service (Paid, Blended, Voluntary). For all analyses a conventional criterion of statistical significance ( $P < 0.05$ ) was used. All data were analysed using SPSS for Windows 22.0. This section will discuss the observations and trends between service type. Baseline data collected included gender, age, ethnicity, marital status, living arrangements, carer status and education status. This section will report the characteristics by service type.

### **7.2.1 Gender**

In UK, the population aged 65 years distributed by gender is 45% male and 55% female (ONS, 2016). The total study sample by gender was 64% female and 36% were men. Therefore, the ratio of women to men was 1.8, a greater ratio when compared with general population estimates. Table 3 provides an overview of the gender by service and geographical type.

Participants by service type reveal that the ratio of female to male is greatest in Blended services (2.4). Staffed services ratio is equal to the sample ratio of 1.8, whilst the male to female ratio is the most equal in Voluntary services (1.1). However, this was not significant when analysed using chi squared test for categorical variables. The ratio of male to female was most equal in the rural service, with urban participants demonstrating a ratio of male to female, 1:2.

### **7.2.2 Age**

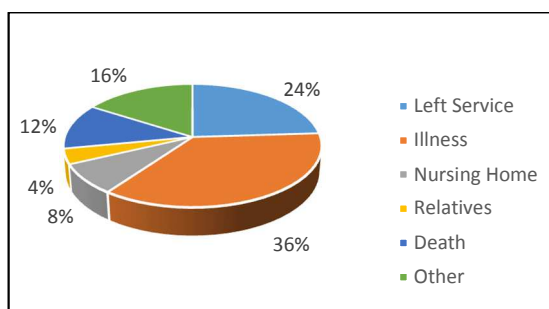
The age range of the total sample population was from 65 -99 years. The oldest male participant was 92 and the oldest female participant was 99. Table 8 illustrates that 84% of those recruited were over the age of 75 years of age. It should also be noted that in terms of gender, 53% of women were over the age of 85 compared with 32% men.

Table 7, illustrates that those attending staffed and Voluntary services were younger than those attending Blended services. One-way ANOVA for continuous variables revealed this was significant,  $F(2, 91) = 2.9, p < 0.05$ . Therefore, despite services supporting people aged 65 years and older, the average age (84.7 years) of those using day care services at Blended service

**Table 6: Quantitative Completion at time points**

Baseline	+6 weeks	+12 weeks
94	73	73

**Figure 10: Reasons for leaving the study**



**Table 7: Baseline characteristics and outcome scores of clients using different types of service**

<i>Column percentages</i>	<b>PAID</b> % (n/N)	<b>BLENDED</b> % (n/N)	<b>VOLUNTARY</b> % (n/N)	<b>P</b>
<b>Gender</b>				
Male	35 (13/37)	29 (9/31)	46 (12/26)	0.40
Female	65 (24/37)	71 (22/31)	54 (14/26)	
<b>Age group</b>				
Mean age	80.9 (±8.2)	84.7 (±4.8)	80.4 (±9.1)	0.04
<b>Marital Status</b>				
Currently Married	27 (10/37)	22 (7/31)	50 (13/26)	0.11
Separated or Divorced	16 (6/37)	10 (3/31)	0	
Widowed	54 (20/37)	68 (21/31)	46 (12/26)	
Never Married	3 (1/37)	0	4 (1/26)	
<b>Social Deprivation</b>				
Living in one of 20% most deprived LSOAs in Eng or Wales	56 (20/36)	24 (7/29)	30 (7/23)	0.02
<b>Mean distance between home and centre</b>	2.0 (±1.4)	2.11 (±1.5)	5.84 (±5.2)	0.001
<b>Living Arrangements</b>				
Partner present no children	16 (6/37)	23 (7/31)	38 (10/26)	0.22
Children are present but no partner	19 (7/37)	19 (6/31)	12 (3/26)	
Partner and children are present	8 (3/37)	0	12 (3/26)	
I live alone	57 (21/37)	58 (18/31)	38 (10/26)	
<b>Carer Status</b>				
I have a carer who is a family member that lives with me	41 (15/37)	29 (9/31)	39 (10/26)	0.25
I have a carer who lives with me but is not a family member	3 (1/37)	0	0	
I have a carer who is a family member that does not live with me	27 (10/37)	32 (10/31)	8 (2/26)	
I have a carer who is not a family member and does not live with me	0	3 (1/31)	8 (2/26)	
I do not have a carer	30 (11/37)	36 (11/31)	46 (12/26)	
<b>Educational Status</b>				
I hold no educational or vocational qualifications	64 (23/36)	36 (11/31)	58 (15/26)	0.13
I have educational or vocational qualifications but not a University degree	33 (12/36)	54 (17/31)	31 (8/26)	
I hold a University degree or above	3 (1/36)	10 (3/31)	11 (3/26)	
<b>Long-term conditions</b>				
Mean no of LTCs reported	4.4 (±1.9)	4.0 (±1.8)	4.7 (±1.8)	0.39
Sensory Loss – Sight	62 (23/37)	74 (23/31)	50 (13/26)	0.17
Sensory Loss - Hearing	28 (10/36)	36 (11/31)	39 (10/26)	0.65
<b>EQ-5D-3L</b>				
Reported problem with Mobility	76 (28/37)	81 (25/31)	73 (19/26)	0.79
Reported problem with Self Care	30 (11/37)	23 (7/31)	42 (11/26)	0.27
Reported problem with Usual Activities	70 (26/37)	71 (22/31)	69 (18/26)	0.99
Reported problem with Pain/Discomfort	41 (15/37)	52 (16/31)	54 (14/26)	0.51
Reported problem with Anxiety or Depression	49 (18/37)	33 (10/30)	50 (13/26)	0.35
Mean VAS score	68 (±22.2)	66 (±18.2)	72 (±20.7))	0.22
Mean number of EQ5 problems	2.6 (±1.4)	3.1 (±1.5)	2.7 (±1.8)	0.22
<b>De Jong SL sub-scale: Reporting 'more or less' or 'no'....</b>				
There are plenty of people I can rely on when I have problems	35 (13/37)	13 (4/30)	40 (10/25)	0.04
Mean EL score	1.2 (±0.95)	1.3 (±0.96)	1.1 (±0.85)	0.77
Mean SL score	0.78 (±1.05)	0.42 (±0.81)	0.88 (±1.25)	0.21
Mean overall loneliness score	2.0 (±1.5)	1.7 (±1.6)	2.0 (±1.9)	0.68

is closer to the oldest old (age 85 years and above), the fastest growing aging group in the UK (Tomassini, 2005).

### 7.2.3 Ethnicity

The ethnicity of the total sample was 100% white. 87 participants reported that they were white British, 1 participant was white Irish, and 6 participants reported that they were white other. Table 9 below illustrates the proportion on the local population for each day care setting that considers themselves to be from an ethnic minority. For services such as the Poppy service, the lack of people attending from ethnic minority background would be expected due to the low proportion of people from ethnic minority background in the local

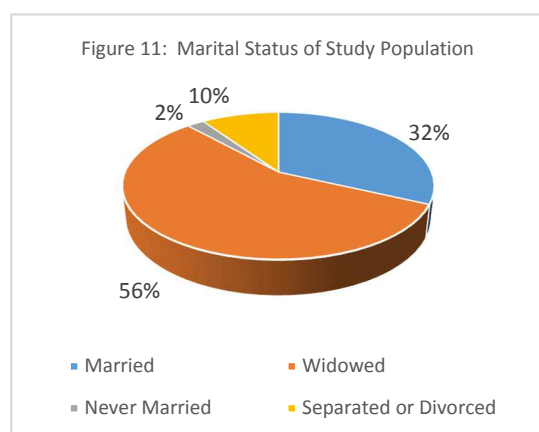
**Table 8: Total Sample by Age and Gender (distribution table)**

Age	65 -74		75-84		85-94		95-104	
	N	%	N	%	N	%	N	%
<b>Total</b>	15	16%	36	38%	41	44%	2	2%
<b>Male</b>	7	20.5%	16	47%	11	32%	0	0%
<b>Female</b>	8	13%	20	33%	30	50%	2	3%

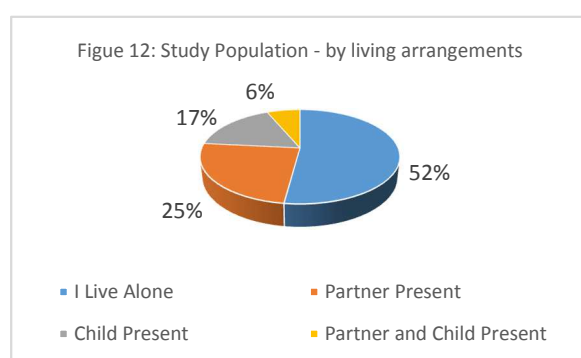
**Table 9 – Day Care Setting and Ethnicity**

Setting	Ethnicity %
Sunflower Paid Service	15.2
Snowdrop Paid Service	21.2
Blackthorn Blended Service	5.3
Birch A & B Blended Service	5.3
Beech Blended Service	4.1
Lilly Blended Service	4.1
Poppy Blended Service	1.2

**Figure 11 – Marital Status**



**Figure 12 – Sample population by living arrangements**



community however for the two Paid staff service, this raises further questions regarding accessibility.

It has been suggested that people from ethnic minorities face barriers to accessing health and social services, resulting in unmet need (Moriarty, 2009). Is this further evidence of a barrier to older people accessing health care? This is discussed further in section 7.6

#### **7.2.4 Marital Status**

People who were widowed were the largest group attending day care. When combined with those who were separated, divorced or never married, 68% of people were not married whilst 32% of people recruited were married.

When comparing the marital status of the sample by service type, more than half of participants were widowed at Paid staff and Blended groups. However, whilst the proportion of those at Paid staff services (54%) was similar to the overall sample (56%) a larger proportion were widowed at the Blended services. Although almost half of those attending Voluntary services were widowed (48%), the highest proportion of the group were married (50%). However, the chi squared test for categorical variable did not reach significance.

#### **7.2.5 Living Arrangement**

Over half (52%) of the sample lived alone and just under half (48%) lived with a family member.

The proportion of those living alone was higher than the sample mean in both the staffed and Blended services and constituted the largest proportion of those attending. However, those living alone was lower for those attending Voluntary services, with those living with a family member making up the largest proportion of the group (62%). However, the chi squared test for categorical variable did not reach significance.

#### **7.2.6 Residential Status**

58% of the sample owned their own home, whilst 42% rented their home. The proportion of home owners and tenants across service type were similar to the overall sample and no differences were found across service type or geographical area.

#### **7.2.7 Carer Status**

For the purpose of the study, a carer is defined as somebody who provides unpaid care for client, usually either a family member, friend or neighbour.

36% of the sample group did not have a carer. 37% of the sample had a carer who lived with them and 27% had a carer who did not live with them.

The proportion of those who did not have a carer in the Blended services was similar to the proportions of the whole sample group. The proportion of those who did not have a carer in staffed services was lower than the sample mean (30%), however 46% of those attending Voluntary services did not have a carer.

#### **7.2.8 Educational Status**

Just over half of the sample (52%) had no educational or vocational qualifications at high school level, whilst 47% had some qualifications, including university degree or above. More than half of those attending Paid staff and Voluntary services had no educational qualifications. However, those that had qualifications were the largest group within the Blended services. A total of 64% of those attending Blended services had qualifications. However, the chi squared test for categorical variables did not find significance. However, the chi squared test for categorical variables did not reach significance.

#### **7.2.9 Deprivation**

36% of the total sample lived in one of the most deprived LSOAs in England or Wales. More than half of those attending Paid staff services lived in a deprived area. Less than a quarter of those attending the Blended services lived in a deprived area. Statistical significance was achieved when comparing the proportion of participants that lived in deprived areas with those attending paid staff services significantly higher when compared with other services.  $\chi^2(2, N=88)=7.6$   $p<0.03$



#### **7.2.10 Distance to Travel**

The sample travelled on average just over 3 miles to attend a day centre. There was a significant difference between the distance to travel for those attending Paid staff and Blended services when compared with those attending Voluntary services with those attending voluntary services travelling further. An analysis of variance showed that the effect of service type on the distance travelled by clients was significant,  $F(2, 91)=15.1, p<0.001$ .

#### **7.2.11 Long Term Conditions**

This section will initially discuss findings in relation to the number of long term conditions (LTCs) and secondly in relation to the types of LTCs.

##### **i) Number of Long Term Conditions**

The number of LTC amongst the sample population ranged from 2-9, the average was 4.3. Across the service type the number of LTCs were similar illustrating that in terms of the number of conditions there was no difference in the number of conditions as expected.

63% of the sample group had some form of sensory loss. Across Blended services three quarters of the group had some form of sight loss, higher than those attending Paid staff services (62%) and Voluntary services (50%), although this was not significant.

33% of the sample population had some form of hearing loss. This was lower for those attending Paid staff services, whilst those attending Blended and Voluntary services had a higher proportion of hearing loss although this was not statistically significant. An analysis of variance showed that the effect of service type on number of LTCs was not significant.

## **ii) Types of Long Term Conditions**

The types of LTC across the sample population are illustrated in figure 13. More than half of total sample had arthritis and heart disease. Over a third of the group had some form of dementia, stroke and mental health illness. Comparing the prevalence of top five LTCs by service type. The most common LTCs for Paid services was arthritis, dementia, stroke, mental health and respiratory disease. There was a similar pattern of prevalence at Blended services with arthritis, dementia, mental health and stroke in the top 5 but diabetes was in the top five instead of respiratory disease. Voluntary services had a different pattern with arthritis still the most common, heart disease, gastric conditions, diabetes and mental health consisted of the five most common conditions.

A higher proportion of people attending Paid services had strokes (49%) compared with Blended (29%) and Voluntary (28%). Paid services also had a higher proportion of people attending with respiratory disease, dementia, neurological condition, and mental health when compared with other services. Blended services had a higher proportion of people with arthritis (76%) and orthopaedic conditions (19%) than at the other services. Voluntary services had a higher proportion of people with diabetes (31%), cancer (15%), renal conditions (15%) thyroid (15%), osteoporosis (23%), gastric (35%) and heart conditions (38%).

## **7.3 Baseline Characteristics by Geographical Type**

### **7.3.1 Gender**

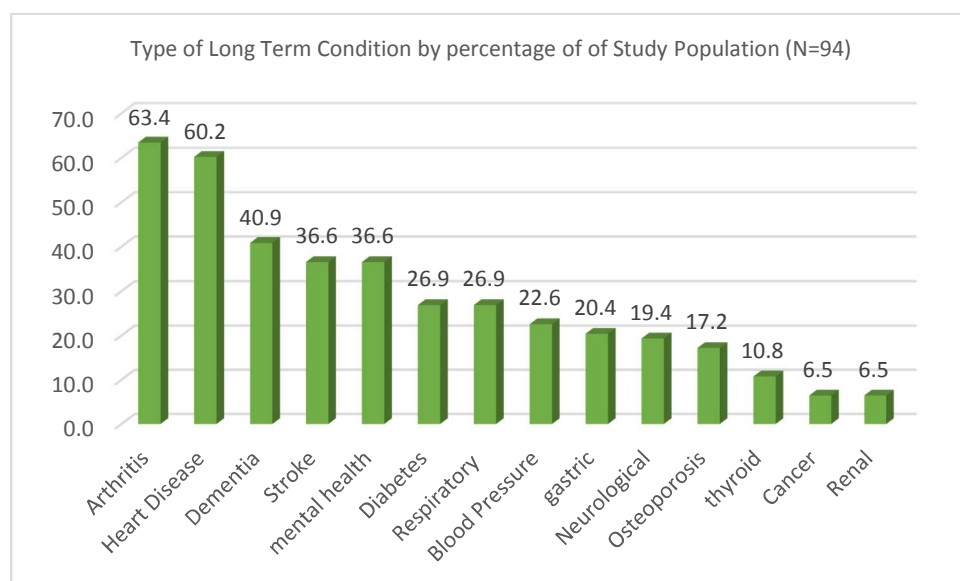
As mentioned in section 7.2.1, the total study sample by gender was 64% female and 36% were men. Therefore, the ratio of women to men was 1.8, a

greater ratio when compared with general population estimates. The ratio of male to female was most equal in the rural service, with urban participants demonstrating a ratio of male to female, 1:2.

### **7.3.2 Age**

As mentioned in section 7.3.2, the age range of the total sample population was from 65 -99 years. The oldest male participant was 92 and the oldest female participant was 99. The mean age of participants in the rural service was higher than those in the urban service. T-test and one way anova for continuous variables were not significant.

**Figure 13: Study Sample - proportion of long term conditions**



**Table 10: Types of Long Term Conditions by Service Type**

LTC	Paid staff %	Blended %	Voluntary %
Stroke	49	29	28
Arthritis	57	71	62
Diabetes	24	26	31
Resp Disease	32	29	15
Dementia	54	39	23
Neurological	22	16	19
Cancer	5	0	15
Renal	8	3	15
Thyroid	11	6	15
Osteoporosis	11	19	23
Gastric	16	13	35
Mental health	43	32	31
Orthopaedic	14	19	12
Heart	22	26	38

### **7.3.3 Ethnicity**

Older people from black and ethnic minorities are less likely to retire to the countryside (Runnymede, 2012), reflected in the low proportion of people from ethnic minority background in the surrounding area of the Lilly rural service. Therefore for such services, a lack of people attending from ethnic minority groups would be more likely. However, in urban areas the level of ethnic minorities at Paid staff services was higher and therefore lack of ethnic minorities using urban services was not expected.

### **7.3.4 Marital Status**

A higher percentage of participants at the rural service were married than those in the urban services. There was a higher proportion of people widowed attending urban services than rural services however statistical significance was not reached.

### **7.3.5 Living Arrangement**

A higher proportion of the participants attending urban services lived alone compared with rural services. 57% of those attending rural services, lived with a family member compared with 46% of those attending urban services.

### **7.3.6 Residential Status**

The proportion of home owners and tenants across service type were similar to the overall sample and no differences were found across service type or geographical area.

### **7.3.7 Carer Status**

Chi squared test for categorical variables did reveal significance for carer status when comparing participants attending rural and urban services.

**Table 11. Baseline characteristics and outcome scores of service users in different locations (urban or rural).**

Column percentages	LOCATION		P
	URBAN %(n/N)	RURAL %(n/N)	
<b>Gender</b>			
Male	33 (27/80)	50 (7/14)	0.24
Female	67 (53/80)	50 (7/14)	
<b>Age group</b>			
Mean age	81.8(±7.7)	83.3(±8.2)	0.49
<b>Marital Status</b>			
Currently Married	29 (23/80)	50 (7/14)	0.29
Separated or Divorced	11 (9/80)	0	
Widowed	58 (46/80)	50 (7/14)	
Never Married	2 (2/80)	0	
<b>Social Deprivation</b>			
Living in one of 20% most deprived LSOAs in Eng or Wales	41 (30/74)	29 (4/14)	0.40
<b>Mean distance between home and centre</b>	2.21(±3.4)	8.31(±5.9)	0.001
<b>Living Arrangements</b>			
Partner present no children	21 (17/80)	43 (6/14)	0.32
Children are present but no partner	19 (15/80)	7 (1/14)	
Partner and children are present	6 (/80)	7 (1/14)	
I live alone	54 (43/80)	43 (6/14)	
<b>Carer Status</b>			
I have a carer who is a family member that lives with me	35 (28/80)	43 (6/14)	0.03
I have a carer who lives with me but is not a family member	1 (1/80)	0	
I have a carer who is a family member that does not live with me	28 (22/80)	0	
I have a carer who is not a family member and does not live with me	1 (1/80)	14 (2/14)	
I do not have a carer	35 (28/80)	43 (6/14)	
<b>Educational Status</b>			
I hold no educational or vocational qualifications	52 (41/79)	57 (8/14)	0.51
I have educational or vocational qualifications but not a University degree	39 (31/79)	43 (6/14)	
I hold a University degree or above	9 (7/79)	0	
<b>Long-term conditions</b>			
Mean no of LTCs reported	4.2(±1.9)	5.2(±1.8)	0.04
Sensory Loss – Sight	63 (50/80)	64 (9/14)	0.90
Sensory Loss - Hearing	33 (26/79)	36 (5/14)	0.84
<b>EQ-5D-3L</b>			
Reported problem with Mobility	78 (62/80)	71 (10/14)	0.62
Reported problem with Self Care	28 (22/80)	50 (7/14)	0.09
Reported problem with Usual Activities	68 (54/80)	86 (12/14)	0.17
Reported problem with Pain/Discomfort	45 (36/80)	64 (9/14)	0.74
Reported problem with Anxiety or Depression	44 (35/79)	43 (6/14)	0.92
Mean VAS score	68(±)	71(±)	0.65(±)
Mean number of EQ5 problems	2.6(±)	3.1(±)	0.22
<b>De Jong SL sub-scale: Reporting 'more or less' or 'no'....</b>			
There are plenty of people I can rely on when I have problems	28 (22/78)	36 (5/14)	0.57
Mean EL score	1.2(±0.9)	1.1(± 0.9)	0.73
Mean SL score	0.68(±1)	0.78(±1.3)	0.72
Mean overall loneliness score	1.9(±1.5)	1.9(±1.9)	0.97

**Table 12: Type of Long Term Condition by geographical area**

<b>LTC</b>	<b>Urban %</b>	<b>Rural %</b>
Stroke	38	29
Arthritis	63	64
Diabetes	25	36
Resp Disease	29	14
Dementia	40	43
Neurological	19	21
Cancer	4	21
Renal	5	14
Thyroid	11	07
Osteoporosis	16	21
Gastric	18	36
Mental health	39	21
Orthopaedic	13	21
Heart	25	29

A larger proportion of those attending rural services did not have a carer when compared with urban services. Although a higher proportion of those attending rural services had a family member living with them who acted as their carer, there was a higher percentage of those attending in urban areas who could rely on carers who did not live with them. The proportion of those at urban services who relied on a carer that did not live with them (29%) was double the proportion of those attending rural services (14%), this reached statistical significance  $\chi^2 (4, N=94) = 10.78, p<0.04$ .

#### **7.3.8 Educational Status**

The level of educational attainment was a similar proportion when comparing urban and rural services however it was noticeable that none of the rural participants had achieved a university degree compared with 9% of those attending urban services.

#### **7.3.9 Deprivation**

A higher proportion of those attending the urban services lives in the most deprived areas compared with those attending rural services, however significance was not reached.

#### **7.3.10 Distance to Travel**

The difference in travel distance from home to the centre was greater again when comparing geographical area. Those attending rural services on average travelled 6.10 miles further than those attending urban services. Statistical significance was achieved using a T-test for continuous variables demonstrating that clients in rural services travelling further than those attending urban services  $t(92)=-806, p<0.001$ .



### **7.3.11 Long Term Conditions**

The proportions of participants with sight loss and hearing loss attending both urban and rural services were similar. However, statistical significance using a T-test for continuous variables was reached, demonstrating that those attending rural services had a higher number of LTCs compared with urban services  $t(92)=-1.987, p<0.05$ .

In rural services, arthritis was the most common LTC that people reported followed by dementia, diabetes, gastric conditions and heart disease and stroke. However there was a noticeable difference between the proportion of people reporting cancer with those in rural areas higher.

## **7.4 Baseline EQ5D3L**

### **7.4.1 Baseline EQ5D3L Total Sample**

The EQ5D3L consists of 5 categorical domains (mobility, self-care, usual activity, pain, anxiety /depression) and a visual analogue score asking participants to rate their overall health state from 0-100. At baseline, the proportion of the total sample reported:

- 77% problems with mobility
- 29% problems with self care
- 70% problems with their usual activity
- 48% pain or discomfort
- 44% anxiety or depression

### **7.4.2 Baseline EQ5D3L by Service Type**

Across service type there was no significant difference for any of the five domains at baseline. It was expected that as those accessing Paid staff

services had to meet the threshold of need, those attending Paid staff services would have a higher level of need. Whilst there was no significant differences between the groups

- The proportion of the people reporting mobility problems was greater for those attending blended and paid staff services than for voluntary services.
- A larger proportion of those attending Voluntary services reported problems with self-care than Paid staff services.
- There were similar proportions of people reporting problems with their usual activities across all service type
- A lower proportion of people reported pain or discomfort in the Paid staff service compared with the total sample.
- More than half of people attending the Voluntary and Blended services reported pain or discomfort, a higher proportion than those in Paid staff services.
- The proportion of people reporting anxiety or depression were similar when comparing Paid staff and Voluntary services. A lower level of anxiety/depression was reported in Blended services.

The average Visual Analogue Score (VAS) score for the total population was 69, the higher end of the scale, ranging from 10-100. There were no significant differences between the service type with the mean score slightly higher for those attending Voluntary services. However those attending Blended services reported a lower mean VAS score when compared with the total sample population.

### **7.4.3 Baseline EQ5D3L by Geographical Area**

By geographical classification there were no significant differences between reported problems of those attending urban or rural services. The proportion of those reporting mobility problems and anxiety or depression was similar for both geographical classifications. It is interesting to note that a trend was identified as those attending rural services reported higher levels of problems with self-care compared with urban services but statistical significance was not reached. They also reported higher problems with performing usual activities and experiencing pain and discomfort however significance was not achieved for these domains. The average VAS score was similar for both urban and rural area at baseline, with no significant differences achieved.

## **7.5 Baseline Loneliness**

### **7.5.1. Baseline Loneliness Total Sample**

The mean score overall for the total population group was 1.9 illustrating mild to moderate loneliness. The mean score for the total study population for emotional loneliness was 1.25 (SD=0.92), mild loneliness and social loneliness 0.66 (SD=1.05) mild loneliness.

### **7.5.2 Baseline Loneliness by Service Type**

There were no significant differences between the levels of loneliness across the service types. However, Table 16 illustrates that those attending Blended service had a slightly lower mean overall loneliness score than the other services and total sample. Those at Blended services had a lower mean social loneliness score but a higher mean emotional loneliness score when compared with the total sample and other service types.

For emotional loneliness for two subscale “I experience a general sense of emptiness” and “I miss having people around me”, a larger proportion of those attending Blended service answered more or less or yes to these 2 questions when compared with the other services. For the third subscale “I often feel rejected, a larger proportion of people attending Voluntary services answered more or less or no. Therefore for all emotional loneliness subscales Paid staffed services had a lower proportion of people answering yes to this component of the scale when compared with either Blended and Voluntary services.

This pattern continued with two of the social loneliness scales; “there are plenty of people I can rely on when I have problems” and “there are many people I can trust completely”. For both scales a larger proportion of those attending Voluntary services, answered more or less or yes when compared to staffed services. Chi squared test for categorical variables revealed statistical significance for the subscale “there are plenty of people I can rely on when I have problems”.

The only subscale that staffed services had the larger proportion of participants answering negatively to (more or less or no) was for the question “there are enough people I feel close to”.

### **7.5.3 Baseline Loneliness by Geographical Area**

There were no differences between the loneliness score when comparing rural and urban services. Differences across the groups were explored further by looking at individual questions within the De Jong Giervald Scale. There were no significant differences across groups apart for one question. Comparison by geographical type did not reveal significant differences between the groups.

A higher proportion of people in urban areas experienced a general sense of emptiness and missed having people around them when compared with rural areas. However, a higher proportion of those attending rural services felt a sense of rejection. The proportion of the groups for two subscales showed similar levels of social loneliness however a higher proportion (36%) of those attending rural services did not feel they had enough people to rely on when they had problems, compared with urban services (28%). This may be related to the earlier finding that those in rural areas had less support from carers who did not live with them.

## **7.6. Outcomes**

The section will initially provide the findings of the EQ5D3L, Loneliness Scale and 12 week satisfaction survey.

The significance of association between baseline attributes/outcome scores and membership of service-type and location groups was tested by the chi-square test for categorical variables and the t-test/one-way ANOVA for continuous measures. Differences in mean scores between the client groups at each time point (baseline, 6 weeks and 12 weeks) were investigated using the t-test or a one-way ANOVA. Repeated-measures two-way anova of variance was used to test for between-group differences in changing scores over time.

### **7.6.1 EQ5D3L Outcomes by Service Type**

This section discusses the findings revealed in Table 13 below. It illustrates, whilst Voluntary services had a slightly higher number of reported problems at baseline it was marginal compared to the other types of service. However, overall at 12 weeks Paid services and Blended services marginally increased

whilst there was a marginal decrease in the overall average number of reported problems in Voluntary services.

Before we examine each domain in more detail, it is useful to look at the Visual Analogue Scores across the service type. As illustrated by the Table 13 average score remains in the top part of the score indicating positive health state. Across all services the score increased by between 4.3 and 5.9 points showing a positive improvement.

To consider changes in characteristics over the first twelve weeks of attending day care services, table 13 reveals that the self-care domain is associated with statistical differences when comparing outcomes for people attending by service type.

At six weeks follow up the proportion of people attending Paid staff services and Blended services reported an increase in problems with self-care, with those attending Voluntary services reporting a reduction in problems. Statistical significance was reached,  $\chi^2 (2, N=73)=7.2$   $p<0.03$ .

The proportion of people reporting mobility problems reduced at Voluntary services but increased at Paid staff and Blended services. However, clients reporting problems with usual activities increased over the first twelve weeks of attendance in all service types (Paid staff, Blended and Voluntary). For the first 12 weeks of attendance those attending Blended services reported a reduction in problems with pain and discomfort however Paid staff and Voluntary services reported an increase in reported problems.

**Table 13. Paid, Blended and Voluntary service users reporting individual EQ5 problems at baseline and follow-up**

		Baseline (P=37,B=31 ,V=26)	6 week (P=28,B=25,V=20)	12 week (P=27,B=27 ,V=19)	P
		%	%	%	
<b>Mobility</b>	<b>Paid</b>	75.7	75.0	77.8	0.79
	<b>Blended</b>	80.6	76.0	85.2	
	<b>Voluntary</b>	73.1	65.0	68.4	
	<b>P</b>	0.79	0.67	0.40	
<b>Self-care</b>	<b>Paid</b>	29.7	46.4	40.7	0.57
	<b>Blended</b>	22.6	32.0	29.6	
	<b>Voluntary</b>	42.3	10.0	26.3	
	<b>P</b>	0.27	0.02	0.53	
<b>Usual activities</b>	<b>Paid</b>	70.3	75.0	85.2	0.90
	<b>Blended</b>	71.0	80.0	74.1	
	<b>Voluntary</b>	69.2	60.0	73.7	
	<b>P</b>	0.99	0.31	0.53	
<b>Pain/discomfort</b>	<b>Paid</b>	40.5	46.4	44.4	0.66
	<b>Blended</b>	51.6	48.0	48.1	
	<b>Voluntary</b>	53.8	50.0	68.4	
	<b>P</b>	0.51	0.97	0.24	
<b>Anxiety/depression</b>	<b>Paid</b>	48.6	46.4	33.3	0.32
	<b>Blended</b>	33.3	40.0	37.0	
	<b>Voluntary</b>	50.0	40.0	15.8	
	<b>P</b>	0.35	0.86	0.27	
<b>Mean no of EQ5 problems</b>	<b>Paid</b>	2.6 (±1.4)	2.9 (±1.36)	2.8 (±1.37)	0.75
	<b>Blended</b>	2.6 (±1.5)	2.8 (±1.36)	2.7 (±1.43)	
	<b>Voluntary</b>	2.9 (±1.8)	2.3 (±1.38)	2.5 (±1.47)	
	<b>P</b>	0.73	0.27	0.80	
<b>Mean VAS score</b>	<b>Paid</b>	68.3 (±22.2)	71.7 (±16.8)	74.2 (±17.6)	0.65
	<b>Blended</b>	66.3 (±18.2)	74.1 (±16.3)	71.9 (±18.84)	
	<b>Voluntary</b>	72.3 (±20.7)	75.8 (±17)	76.8 (±19.13)	
	<b>P</b>	0.55	0.72	0.68	

Those attending Voluntary services reported a reduction in anxiety and depression problems over the first twelve weeks of attendance. This was also the case for those attending Paid services however problems with anxiety and depression increased slightly in Blended services.

Therefore, the reported outcomes at twelve week follow up provide evidence that those attending services supported by volunteers (either Voluntary services or Blended) reported a reduction in problems, confirming favourable outcomes at twelve weeks follow up.

#### **7.6.2 EQ5D3L Outcomes by geographical area**

This section reviews the findings revealed in Table 14 below. The previous section demonstrated differences in the proportion of reported problems by service type over the first twelve weeks of attendance. Comparison by geographical area did not reveal a statistical difference between urban and rural areas. At twelve weeks there were reported increases in problems relating to mobility, usual activities and pain or discomfort at both urban and rural services. However, as with the previous section there were reported reductions in problems with self-care.

Those attending rural services reported a reduction in problems at 12 weeks compared to a reported increase at urban services. Whilst there was a reduction in anxiety and depression in both urban and rural services, the reduction was greater at rural services. Therefore, there were demonstrable favourable outcomes in rural services over the first twelve weeks but more specifically related to problems of self-care and anxiety or depression. The comparison of the number of mean problems reported in rural services



decreased over the first twelve weeks of attendance but increased slightly in urban services.

### **7.6.3 Loneliness Outcomes**

The levels of loneliness were also examined in terms of the changes from baseline to 12 weeks on the level of loneliness, rather than just the score. Table 18 shows the level of loneliness with a score of 5-6 representing intense loneliness. It can be seen that across the total sample that of those that had intense loneliness 83.4% changed category to a lower level of loneliness for example, none, mild and moderate. 66.7% reduced from moderate (3-4) to mild level of loneliness (1-2) and 20% of those with mild levels of loneliness reduced to no level of loneliness.

### **7.6.4 Loneliness outcomes by Service Type**

The Chi square test for categorical variables and T-test for continuous variables was used to assess change in measured loneliness from baseline to final follow-up. Table 16 provides the mean total loneliness score per service group. Although statistical significance was not reached when comparing the three service groups, the change in mean between baseline and 12 weeks did reduce in Blended services and Voluntary services but increased in those attending Paid Staff services.

In order to examine this more closely, the mean scores for emotional loneliness and social loneliness were compared by service group. The results for total loneliness showed the mean score for those attending Voluntary and Blended services reduced over 12 weeks whilst the mean score for those attending Paid Staff services increased. However, when the social loneliness group means across the three services were analysed from baseline to 12

**Table 14. Urban and rural service users reporting individual EQ5 problems at baseline and follow-up**

		Baseline (U=80, R=12)	6 week (U=61, R=12)	12 week (U=61, R=12)	P
		%	%	%	
Mobility	Urban	77.5	73.8	78.7	0.79
	Rural	71.4	66.7	75.0	
	P	0.62	0.61	0.78	
Self-care	Urban	27.5	34.4	32.8	0.57
	Rural	50.0	16.7	33.4	
	P	0.09	0.23	0.97	
Usual activities	Urban	67.5	72.1	75.4	0.90
	Rural	85.7	75.0	91.7	
	P	0.17	0.84	0.21	
Pain/discomfort	Urban	45.0	45.9	47.5	0.66
	Rural	64.3	58.3	75.0	
	P	0.18	0.43	0.08	
Anxiety/depression	Urban	44.3	41.0	32.8	0.32
	Rural	42.9	50.0	16.7	
	P	0.92	0.56	0.27	
Mean no of EQ5 problems	Urban	2.6 (±1.5)	2.7(±1.36)	2.7(±1.42)	0.26
	Rural	3.1(±1.7)	2.7(±1.38)	2.9(±1.5)	
	P	0.22	0.99	0.60	
Mean VAS score	Urban	68.4(±20.5)	74.5(±16.7)	74.3(±18.85)	0.70
	Rural	71.1(±21.3)	69.6(±16.9)	72.5(±19.1)	
	P	0.65	0.35	0.76	

**Table 15 – Total Sample, proportion of service users changing loneliness status from baseline to 12-week follow-up**

Row percentages	De Jong score at 12-week follow-up					
	0	1-2	3-4	5-6		
De Jong score at baseline						
0 (n=15)	60.0	40.0	0	0	100	
1-2 (n=35)	20.0	57.1	20.0	2.9	100	
3-4 (n=15)	20.0	46.7	33.3	0	100	
5-6 (n=6)	16.7	16.7	50.0	16.7	100	

**Table 16: Change in De Jong-measured Total Loneliness for Paid, Blended and Voluntary service users.**

	Total Loneliness score at baseline (P=37; B=31; V=26)	Total Loneliness score at 6 weeks (P=27; B=25; V=19)	Total Loneliness score at 12 weeks (P=25; B=28; V=18)	
	Mean	Mean	Mean	P
Staffed	2.03(±1.5)	2.11(±1.54)	2.80(±1.23)	0.72
Blended	1.71(±1.6)	1.24(±1.42)	1.29(±1.3)	
Voluntary	2.00(±1.9)	1.79(±1.68)	1.65(±1.6)	
P	0.68	0.13	0.15	

**Table 17: Change in De Jong-measured Emotional Loneliness for Paid, Blended and Voluntary service users**

	EL score at baseline (P=37; B=31; V=26)	EL score at 6 weeks (P=27; B=25; V=19)	EL score at 12 weeks (P=25; B=28; V=18)	
	Mean	Mean	Mean	P
Staffed	1.24(±0.95)	1.44(±0.99)	1.48(±0.97)	0.47
Blended	1.29(±0.96)	0.96(±0.99)	1.07(±1.01)	
Voluntary	1.12(±0.85)	1.16(±1.07)	0.94(±1.16)	
P	0.77	0.22	0.22	

**Table 18: Change in De Jong-measured Social Loneliness for Paid, Blended and Voluntary service users**

	SL score at baseline (P=37; B=31; V=26)	SL score at 6 weeks (P=28; B=25; V=19)	SL score at 12 weeks (P=25; B=28; V=18)	
	Mean	Mean	Mean	P
Staffed	0.78(±1.05)	0.64(±0.96)	0.52(±0.73)	0.91
Blended	0.42(±0.81)	0.28(±0.87)	0.21(±0.65)	
Voluntary	0.88(±1.25)	0.74(±1.05)	0.44(±0.85)	
P	0.21	0.26	0.32	

**Table 19: Baseline and follow-up De Jong loneliness (total) scores for urban and rural service-users.**

	Total loneliness score at baseline (U=80 R=14)	Total loneliness score at 6 weeks (U=60 R=11)	Total loneliness score at 12 weeks (U=60 R=11)	
	Mean	Mean	Mean	P
Urban	1.91(±1.5)	1.67(±1.55)	1.57(±1.36)	0.36
Rural	1.92(±1.9)	2.18(±1.83)	1.55(±1.71)	
<b>P</b>	0.97	0.33	0.96	

**Table 20: Baseline and follow up De Jong loneliness Emotional Loneliness scores for urban and rural service users**

	EL score at baseline (U=80 R=14)	EL score at 6 weeks (U=60 R=11)	EL score at 12 weeks (U=60 R=11)	
	Mean	Mean	Mean	P
Urban	1.24(±0.92)	1.15(±1.00)	1.23(±1.05)	0.11
Rural	1.14(±0.95)	1.45(±1.03)	0.91(±1.14)	
<b>P</b>	0.73	0.36	0.37	

**Table 21: Baseline and follow up De Jong loneliness Social Loneliness scores for urban and rural service users**

	SL score at baseline (U=80 R=14)	SL score at 6 weeks (U=61 R=11)	SL score at 12 weeks (U=60 R=11)	
	Mean	Mean	Mean	P
Urban	0.68(±1.02)	0.51(±0.97)	0.33(±0.72)	0.86
Rural	0.79(±1.25)	0.73(±1.02)	0.64(±1.03)	
<b>P</b>	0.72	0.51	0.23	

**Table 22: Baseline characteristics and change in number of EQ5 problems reported from baseline to final follow-up**

Type of service	No Change or reduced number of problems	Increase in problems	
Paid (n=29) %	55.2	44.8	0.16
Blended (n=28) %	64.3	35.7	
Voluntary (n=21) %	81.0	19.0	
<b>Location</b>			
Urban (n=65) %	61.5	38.5	0.11
Rural (n=13) %	84.6	15.4	
<b>Gender</b>			
Male (n=29) %	55.2	44.8	0.14
Female (n=49) %	71.4	28.6	
<b>Long-term conditions</b>			
Mean no of LTCs reported	4.4	3.6	0.04

weeks, it could be seen that the group mean score reduced across all services. Therefore lack of reduced loneliness for those attending the Paid staff services was connected to levels of emotional loneliness rather than social loneliness.

#### **7.6.5 Loneliness outcomes by Geographical area**

Tables 19, 20 and 21 illustrate the findings when comparing outcomes by geographical area. In both urban and rural areas the levels of loneliness (total, emotional and social) all decreased at 12 weeks attendance however the level of reduction in emotional loneliness was minimal at urban services. Similarly whilst social loneliness did reduce at rural services the reduction was more evident in urban services. This reveals the impact on the different types of loneliness day care has whether it is based in an urban area or rural area.

#### **7.6.6 Summary of EQ5D3L and De Jong Giervald outcomes**

To summarise, Table 22 illustrates that when comparing service type, a higher percentage of clients attending Voluntary services reported no change or reduced number of problems. To firstly look at EQ5D3L the increase in reported problems is lower at Voluntary services than in Blended and Paid staff services, but statistical significance was not reached. There was a trend in reported problems when comparing urban and rural services with a lower proportion of people in rural areas reporting an increase (not significant).

There was a trend observed when comparing changes in reported problems by gender with a lower proportion of women reporting increases in problems than their male counterparts, but this did not reach significance.

In addition to the information above, there was an association between the changes in number of reported problems and the number of LTCs. Although it may be expected that any increase in problems may be more common for

**Table 23: Summary of Outcomes by Service Type at 12 weeks attendance**

	<b>Paid Staff</b>	<b>Blended</b>	<b>Voluntary</b>
	<b>EQ5D3L – favourable outcomes reported at 12 weeks</b>		
<b>Mobility</b>	No	No	<b>Yes</b>
<b>Self-care</b>	No	No	<b>Yes</b>
<b>Usual Activities</b>	No	No	No
<b>Pain /Discomfort</b>	No	<b>Yes</b>	No
<b>Anxiety /Depression</b>	<b>Yes</b>	No	<b>Yes</b>
<b>Mean number of EQ5D3L problems</b>	No	No	<b>Yes</b>
<b>Mean VAS Score</b>	<b>Yes</b>	<b>Yes</b>	<b>Yes</b>
	<b>Loneliness Scale</b>		
<b>Total Loneliness</b>	No	<b>Yes</b>	<b>Yes</b>
<b>Social Loneliness</b>	<b>Yes</b>	<b>Yes</b>	<b>Yes</b>
<b>Emotional Loneliness</b>	No	<b>Yes</b>	<b>Yes</b>

**Table 24: Summary of Outcomes by Geographical Area at 12 weeks attendance**

	<b>Urban</b>	<b>Rural</b>
	<b>EQ5D3L – favourable outcomes reported at 12 weeks</b>	
<b>Mobility</b>	No	No
<b>Self-care</b>	No	<b>Yes</b>
<b>Usual Activities</b>	No	No
<b>Pain /Discomfort</b>	No	No
<b>Anxiety /Depression</b>	<b>Yes</b>	<b>Yes</b>
<b>Mean number of EQ5D3L problems</b>	No	<b>Yes</b>
<b>Mean VAS Score</b>	<b>Yes</b>	<b>Yes</b>
	<b>Loneliness Scale</b>	
<b>Total Loneliness</b>	<b>Yes</b>	<b>Yes</b>
<b>Social Loneliness</b>	<b>Yes</b>	<b>Yes</b>
<b>Emotional Loneliness</b>	<b>Yes</b>	<b>Yes</b>

people who have a higher number of LTCs, the table below demonstrates that this is not the case. Those reporting an increase in problems had a lower number of long terms conditions (3.6) than those who reported no change or reduced number of problems (4.4) at the significance level,  $t(76)=3.14$ ,  $p<0.05$

Table 23 summarises changes to outcomes by service type and Table 24 summarises outcomes by geographical service.

#### **7.6.7 Prediction of outcomes**

Univariate logistic models were run to estimate the effect of type and location of service on the likelihood of 'any improvement' in outcome defined as a reduction in loneliness score, decrease in number of reported EQ5 problems and an increase in VAS global health rating from baseline to twelve weeks.

Clients attending Blended services were twice as likely to experience a reduction in De Jong loneliness score between baseline and their final follow-up but this did not reach statistical significance compared to clients attending a Paid staff service. The elderly people receiving a service delivered by Voluntary staff also had a raised (but non-significant) likelihood of reporting reduced loneliness compared to Paid staff service  $OR=2.46$ , 95% CI 0.74-8.26,  $P>0.05$ . Compared to the clients attending Paid staff services, those attending a Blended service had a raised likelihood of experiencing a reduction in the number of reported EQ5 health problems but this did not reach statistical significance. The Voluntary service group had a statistically significant increase, in the likelihood of reporting fewer health problems in follow-up ( $OR=3.45$ , 95% CI 1.01-12.8,  $P<0.05$ ) compared to Paid staff service. However, in terms of reporting an improvement in the global health rating (VAS) from baseline to follow-up, the Voluntary service clients had a reduced

likelihood compared to the Paid staff services (OR= 0.67, 95% CI 0.21-2.17,  $P>0.05$ ). Users of Blended services had raised (but non-significant) odds of reporting a higher VAS rating (OR=2.0, 95% CI 0.64-6.29,  $P>0.05$ ).

Clients of services delivered in rural areas were more likely (than their urban counterparts) to report a reduction in loneliness (OR=1.49, 95% CI 0.43-5.24,  $P>0.05$ ) and fewer EQ5 health problems (OR=3.44, 95% CI 0.70-16.8,  $P>0.05$ ). However, urban service-users had an increased likelihood of reporting an improvement in the VAS rating from baseline to follow-up (OR= 1.72, 95% CI 0.49-5.88,  $P<0.05$ ).

#### **7.6.8 Satisfaction Survey**

73 participants completed a satisfaction questionnaire at 12 weeks follow up (for questionnaire see Appendix 12). 86% of Participants still attending day care at 12 weeks stated that their life since starting the service was better or much better, 12% said it was the same and 1.4% said it was worse. Therefore overall those attending day care at 12 weeks rated the service favourably. However, it should be noted that those who were no longer attending, possibly for negative reasons were not followed up once they left the service. The fact that those completing the service remained and had not opted to leave indicates a favourable experience of the service.

The follow up questions in the survey asked participants to explain why their life was better or worse, indicate anything positive they liked at the service and anything negative. Table 25 gives an overview of the types of responses reported in the questionnaire. The answers were provided in a qualitative format and therefore included and discussed further in the following chapter.



**Table 25: 12 Week Satisfaction survey – Client responses**

<b>Self reported why life better / same worse since attending day care</b>	<b>N</b>	<b>%</b>
Interaction/meeting people	32	44
Company	15	21
Activity	13	18
Food	9	12
Staff or Volunteers	8	11
Something to look forward to	7	10
Prevent Solitary life at home	7	10
Change of scene	3	4
Reduce Anxiety	3	4
Feel secure and safe	2	3
Respite	1	1

## 7.7 Summary

This chapter addresses the gap in the literature by providing an understanding of the characteristics of the users of day care services and explores attainable outcomes (by type and geographical area). The comparison by type and area enables services to use the findings to assess if they are accessible, equitable and effective for their clients.

The concept of multiple long term conditions is central to this thesis. It was expected that as those attending Paid staff services did so after a needs assessment that reached the required needs threshold, the number of LTCs reported would be higher in Paid staff services. However, this was not the case demonstrating that charities and Voluntary groups are managing the same level of need when considering multiple LTCs. Those at rural services reported a statistically significantly higher number of long terms conditions when compared with urban services  $t(92)=-1.987, p<0.05$ .

Analysis of outcomes reveal that the types of conditions by service a pattern emerges that suggests that the diagnosis may be a factor in accessing the Paid staff services. The most common LTCs reported in Paid staff services were similar to those in Blended services. Conditions such as arthritis, dementia and stroke were the most dominant reported conditions in rural areas, however there was a greater proportion of people reporting cancer in rural areas compared with urban areas. With regards to stroke and dementia diagnosis, it could be suggested that those accessing Paid staff services may meet the needs threshold due to the issues around personal care that such a diagnosis brings in terms of the associated disability.

However, analysis of the baseline EQ5D3L data demonstrated that the reported problems with self-care was higher at Voluntary services and lower at Paid staff services. There was a greater proportion of people using rural services that reported problems with self-care demonstrating a trend compared with those in urban areas but the trend did not reach statistical significance.

Those reporting an increase in EQ5D3L problems at 12 weeks had a lower number of LTCs. Those reporting a decrease in long term conditions had a significantly higher number of LTCs. This suggests that day care was more effective for people with a greater number of conditions.

The quantitative data revealed the prevalence of dementia in all services ranged from between a third of new participants in Voluntary services and half of new participants in Paid staff services. All participants reporting dementia were in the early stages of the condition.

Statistical analysis also revealed that people attending Blended services were significantly older than those attending Voluntary and Paid staff services  $F(2, 91) = 2.9, p < 0.05$ . Those attending rural services were on average older (83.3) than in urban areas (81.8) although this was not significant. The average age of the sample was over 80 years, with those attending Blended services close to the older old category of 85 years. Clients were comparable age at both paid and voluntary services. Clients accessing the service were all white, with clients from ethnic minorities not accessing the services engaged with the study. This will be discussed further in chapter 10.2.

Baseline data provided further insight into access issues around for older people using day care services. The distance travelled by clients of day care varied significantly between services with those attending Voluntary services travelling further than those at Paid staff and Blended services and those attending rural service travelled the greater distance  $t(92)=-806, p<0.001$ . In terms of support to access the service, there was a higher proportion of people attending Paid services who reported that they did have a carer but the carer did not live with them. In urban services this reached statistical significance when compared with rural areas. This demonstrates further barriers for people accessing day care in rural areas.

It was revealed that a lower proportion of people attending Paid staff services reported pain at baseline, when compared with Blended and Voluntary services. This could suggest that accessing Paid services may be associated with greater access to management of LTCs via medication. A higher proportion of people attending Voluntary services reported problems with anxiety and depression, compared to Paid and Blended services.

In terms of the level of support people felt they had, a higher proportion of people in Paid staff services and Voluntary services did not feel that they had people that they could rely on, reaching statistical significance. There was a reduction in social loneliness scores across all three service types. However total loneliness scores increased in Paid services but decreased in Blended and Voluntary services. This was due to the increase in emotional loneliness at Paid staff services. However, emotional loneliness scale also decreased in Blended and Voluntary services. Therefore, analysis of loneliness scores demonstrated that volunteer provision is effective in producing favourable

outcomes for people experiencing both emotional and social loneliness. There was a trend that a reduction of loneliness was more favourable for women attending services but this did not reach statistical significance.

The pattern was similar when analysing changes in outcomes for clients attending rural services. There was a reduction in total loneliness and social loneliness scores at twelve weeks for clients attending both urban and rural services. Whilst there was a slight decrease in emotional loneliness scores at urban services, there was a greater observable reduction in emotional loneliness scores for those attending rural services over the first twelve weeks.

The satisfaction survey undertaken by those attending services at 12 weeks was predominantly favourable, indicating that irrelevant of changes in outcomes, clients reported in their own words their high levels of satisfaction with the services they attended. The following chapter will present the findings from the client's perspective using data obtained during semi structured interviews, observations and client 12 week satisfaction surveys.

## **8. Client Findings Qualitative**

### **8.1 Introduction**

In accordance with chapters six and seven, the findings reported in this chapter aim to provide an understanding of the outcomes from the client's perspective using data collected during observations, semi structured interviews with clients and qualitative data from the 12 week satisfaction survey. For the purpose of this chapter the 20 clients who were interviewed have been given a pseudonym in Table 26 below to maintain confidentiality

Participants' transcripts had two strong characteristics evident. The first pertaining to the type of people accessing day care (section 8.2.1) and the second, common when people articulated the elements of day care they enjoyed (section 8.5).

The structure of the chapter follows a similar format to chapter 6, whereby evidence found to support findings in that chapter are reported from the viewpoint of those using the service. Access to services discusses the trigger for the referral, moving onto findings relating to transport, food, activities, group dynamics and impact for clients.

### **8.1 Trigger**

It became clear that participants did not provide one particular incident that had led them to access day care services but combined events with the common element of loss. For some this was the presence of a long term health condition combined with bereavement; for others declining health leading to

loss of independence in terms of anxiety leaving the home or losing the ability to drive; bereavement followed by relocation.

The reason for accessing day care was often described from years before rather than a more recent event that had triggered the referral.

*I had lots of lovely neighbours where I used to live and I never felt the need to go anywhere, other than the friends that were neighbours that kind of thing and er the people I've known for a lifetime and that was lovely and it was very traumatic leaving there.....*

*I didn't have any communication but he told me he would speak to the DVLA and er then a couple of weeks after I was sent, well my daughter, I was going out and I thought .....but she said "you can't drive mum" and I couldn't understand what she was talking about she said, "you can't drive" and I said (sounding angry as she says this )"I don't understand what you're saying". And she said you've lost your license. And they'd notified my daughter but not me and I thought that that was quite callous. You, anyway, I wasn't expecting that and I don't drive, well I can't drive anymore.*

***Anne, Blended /Urban Service***

**Table 26: Pseudonyms for client names for qualitative interviews.**

Name	Service /Geography	Age	Living & Carer Arrangements	LTC
Bob	Blended/Urban	90	Widowed, lives in a family annexe, has a family carer	arthritis, early stage dementia respiratory disease visual and auditory sensory loss
Norman	Voluntary / Rural	75	Married, lives with wife, has a family carer	Arthritis, diabetes, respiratory disease, early stage dementia, Neurological disorder, psychotic disorder, heart disease, hearing loss
Anne	Blended/Urban	83	Widowed, lives in family annexe , has a family carer	Stroke, arthritis, Respiratory disease, early stage dementia, neurological condition, renal, mental health, visual and auditory sensory loss
Maisie	Paid Staff / Urban	76	Married, lives with family carer	Arthritis, gastric, high blood pressure, visual loss and auditory loss
Edith	Paid Staff /Urban	78	Divorced, lives with family carer	Stroke, arthritis, diabetes, osteoporosis, mental health, visual sensory loss
Val	Blended/ Urban	82	Widowed, lives alone, does not have a carer	Tinnitus, respiratory disease, auditory loss
James	Paid/Staff Urban	80	Divorced, lives alone, does not have a carer	Stroke, arthritis, early stage dementia, gastric, mental health, heart condition, sight and hearing loss
Mary	Paid / Staff Urban	84	Married, lives with family	Respiratory, osteoporosis, depression and bipolar
Eric	Blended/Urban	85	Widowed, lives alone, has a carer	Stroke, diabetes, visual loss,
David	Voluntary / Urban	78	Never married, lives alone, does not have a carer	Arthritis, osteoporosis, gastric, mental health , hearing loss
Pam	Blended/Urban	84	Widowed, lives alone, does not have a carer	Arthritis, diabetes, osteoporosis, depression
Kate	Blended/Urban	87	Widowed, lives alone, does not have a carer	Arthritis, osteoporosis, macular degeneration, sight loss, hearing loss
Dot	Blended/Urban	79	Married, lives with partner, has a family carer	Arthritis, diabetes, respiratory disease, thyroid, gastric, heart disease,
Joan	Paid / Urban	92	Widowed, lives with family, has a carer	Stroke, arthritis, respiratory disease, dementia, renal, mastoid ear, heart condition, visual loss and hearing loss
Jack	Voluntary / Rural	72	Married, lives with partner, does not have a carer	Stroke, arthritis, early stage dementia, neurological condition, renal, gastric, anxiety, depression, visual loss
Emily	Voluntary Rural	90	Widowed, lives alone, has a carer	Heart condition, thyroid, neurological condition, blood disorder
Ruth	Paid, Urban	86	Widowed, lives alone, family carer	Heart condition, stroke, rheumatoid arthritis, diabetes, early stage dementia, parkinsons, thyroid, macular degeneration, hearing loss
Elisabeth	Voluntary / Rural	84	Widowed, lives alone, does not have a carer	Arthritis, osteoporosis, gastric, fibromyalgia, spinal problems,
Norah	Voluntary / Rural	87	Widowed, lives alone, does not have a carer	Arthritis, heart condition, neurological problems, sight and hearing loss
Theresa	Voluntary/rural	73	Married, lives with partner, does not have a carer	Diabetes, mental health, high blood pressure, sight loss



*“Well er I suffered a stroke, two well almost two years ago and my wife was in a nursing home and I er was living alone and not able to do anything for myself, my son used to do my garden and his wife used to do my shopping my cleaning, my laundry, and erm I was finding it increasingly difficult for them to be looking after me.....erm from then on I used to visit my wife, four times a week er but she, er she died last July*

***Eric Blended/Urban Service***

As with the second quote above, many participants referred to their concern for family members that they were living with. The respite element of the service for family members was referred to by clients as a reason for accessing services.

*I felt really to be honest, I was putting too much pressure on M (wife) really, I ...she was here at my beck and call and I thought that's not fair so I'll have to do something about it myself.*

***Norman, Voluntary Rural Service***

*“I was getting, one of my daughters lives with me you see, and I wanted to try to get her a bit of time to herself.*

***Joan, Paid Urban Service***

The onset of long term conditions (LTCs) and declining physical health resulted in clients becoming housebound, that in turn affected relationships for those who lived with family members.

*“....to get away from him at home..... ...you see he goes to bed at 7 o’clock cos he won’t watch what I watch and all of the best things are on later on”*

***Maisie, Paid Urban Service***

*“don’t want to think oh I’ve got to take my mother, oh, they do it a lot. They don’t mean to but the relatives have that, oh who’s going to do that for my mum and I don’t want to get into that rut”*

***Joan, Paid Urban Service***

For those living alone, becoming housebound combined with loss of physical function within the home restricted hobbies or interests that they could undertake.

*“Well my health was deteriorating but not to the ...just so I couldn’t walk so well. I couldn’t walk to town, which I used to do and even go to supermarket and things but I started going down a bit but I can’t remember how long ago I started like that but even if you didn’t know the people, you got to know them.....but as you come into your house things get smaller and smaller and there’s no opportunity for you, you know to express yourself”*

***Emily, Voluntary Rural Service***

*I remember going to a shop once to buy material for this extremely difficult pattern and I was in the shop for about 2 hours getting all these bits (laughter), it was lovely.*

**Norah, Voluntary Rural Service**

For those who had relocated to be nearer family, readjusting to new homes and neighbourhood was difficult.

*“I could go out in the garden or its surprising when you’re doing a garden how people stop and have a natter, whereas here well of course you can go out in the garden but there’s not many people”*

**Dot, Blended/Urban Service**

Disability due to LTCs meant that by being housebound anxiety grew from long periods of isolation.

*“Well the district nurses they kept on to me about you this you know, by this time I was getting frightened about strangers you know what I mean. Because I couldn’t get out and nobody came to see me”.*

**James, Paid/Urban Service**

## **8.2. Access**

### **8.2.1 Referral to day care.**

In terms of accessing services those attending the staffed services had to meet a needs threshold via a social worker assessment. Therefore, the route to access the service was via this route. Those attending Blended services and Voluntary services accessed the services themselves or family, on occasion following health or social work professionals' recommendation. There were two types of narratives evident for this process. Those that required support to find, access and visit services and those that had the confidence and the ability to negotiate services when needed.

### **Requiring Support**

*"Well I'd been having a bad time nervous wise and I got referred to the doctor at the hospital, and he specialises in dealing with people who have problems like I have. And er he told me about here and he started the ball rolling about how to get in touch to here. So that's how it started"*

***Anne, Blended Urban Service***

### **Self starter able to access services independently**

*"Yes I just joined in and I wasn't invited or anything (laughter), and you know I'll go until they turn me out (laughter)"*

***Val, Blended Urban Service***

*"One evening that they were advertising for volunteers for the centre and I thought I don't want to be a volunteer there but I would like to go there"*

**Theresa Female, Voluntary Rural Services**

Whatever service clients attended there were various strategies used to support participants over any anxiety the commencement of the service may cause.

*“And they said alright don’t worry about it you can go for the day and if you don’t like it you don’t have to go any more. So I carried on....”*

**Pam, Blended Urban Service**

*“And when the centre came up, I was a bit apprehensive really but she was keen on me on giving it a try, so I gave it a try and I haven’t really looked back since...I haven’t looked back”.*

**Norman, Voluntary Urban Service**

As with the evidence above most services allowed participants to visit or take part in a taster day before making a decision about attending the centre. The taster day also enabled services without the benefit of a social work referral to undertake an assessment of the person’s needs to ensure the service could meet their needs. The rural service also visited people at home before they started at the centre and Blended services discussed the person’s needs with them over the phone.

*“She came here and said what they were doing and said they were looking for people who can do a little a bit and would like company for the day more or less and I thought oh that’s great”.*

**Emily, Voluntary Rural Service**

Observations at one service took place when three new starters were visiting the centre.

*An advocate from a Charity attended the centre with 2 female new starters. Both had been identified by the health service. The third person (male) had been in hospital and was attending with a social worker. The latter was overwhelmed by the attention received from some members of the group. The staff member facilitated the conversation identifying places of work and similar interests with other members. The new starter did not stay longer than the allotted hour. The female new starters did return to the centre.*

### ***Fieldwork note, Blended Urban Service***

The observation above highlights the importance of group dynamic, discussed further in section 8.6.

As discussed in chapter 6, there were various levels of integration with services in order to provide transport, activities and food. Each aspect will be discussed using evidence from interviews, with the integration of services discussed in more detail at the end.

### **8.3. Transport**

Chapter six provides an overview of the provision of transport for those accessing day care services. For those meeting the needs level threshold transport was available to support those with physical disabilities using either a mini bus provided by the centre or community transport. This type of service was also available for those accessing Blended and Voluntary services although many did not use this

### **8.3.1 Disabled Transport Minibus (Community or Centre).**

There was negative comments from participants in relation to the length of the journey, particularly in winter with some participants who were able to finding alternatives to travelling by this method. Despite the transport provision used specifically adapted for people of this age group with disabilities, there were issues for people during the journey.

*“some of them were disabled and not being able to go up the step so they have to open the back and get them in and I was cold, well colder than its been. And so and er I said I’d ...well that was the only thing I didn’t like..... And now I don’t go on the bus in the morning..my son or my daughter take me on there.... can go direct then and I don’t have to stop and fetch everybody, bless ‘em and they come from quite a way”*

#### **Emily, Voluntary Rural Service**

*“its alright but its like there’s springs under my chair and you know these things in the road that make you slow down ..... I count 30 on the way from my home to here and some of them your sat there and you (points up) and you actually leave the chair (laughter). Some they’re every 10-15 yards in some places” [referring to pain]*

#### **James, Paid Urban Service**

For those utilising transport provided by the centre, cuts to budgets had meant that length of journey for clients was longer as services had been relocated.

*“we were late this morning so what with the different man and you get a cup of tea and that and toast and next thing they’re calling you for dinner at 12pm. That’s why I said no just give me a sandwich*

*'cos I was leaving the dinner and I say there was a long face on them"*

### ***Mary, Paid Urban Service***

*Group had had their welcome drink and snack but the community transport had not arrived so group was delayed and waiting to start an activity. As no communication between day care and the transport provider, leader unsure whether due to absence of clients or problem with transport. Caused delay in routine*

### ***Fieldwork Observation, Blended Service***

This didn't just affect the routine at the centre at the start of the day but also at the end.

*The only way it could be improved is if I could stay 'til the end but the bus always picks me up early*

### ***12 weeks satisfaction questionnaire response at Blended service***

The length of journey could often delay the routine throughout the day in terms of activities and food provision. In rural areas there was a limit to how far the community transport could travel to collect with clients further afield relying on help from friends. However as friends aged a client highlighted the difficulty she had asking for help.

*Because the lady who takes me there, also comes to the door, but she is elderly as well so you can't lean too much on her. You know and another thing and I can't ask them to put these walking things*



*into the car. It's too much of an imposition, it's not right you know.  
My kids, I ask my kids to do it but not friends, it's not good.*

**Norah, Voluntary Rural Service**

As discussed in section 7, at the rural service the length of trips before and after the centre can be quite lengthy. One participant commented on enjoying these trips and an incident that the driver changed the route so that an isolated lady could see a place where she had lived in her earlier years.

*“you know there's one lady there who is a character and the bus goes all over but she gets dropped off before the other place.....she commented she hadn't been there for years, she asked and asked and as he's ever so good he asked if I minded and I said no...oh she was delighted...she hadn't been there for years, she grew up there”*

**Elisabeth, Voluntary Rural Service**

The Sunflower Paid service had undergone a reorganisation so that clients now travelled further from other areas on the transport but some clients enjoyed seeing where people lived and it facilitated friendships.

*“I'm noseey you know, (laughter) but one lady used to come here but she only lived around the corner from me when we came on the bus, so now on a Monday I go round and have a chat as well as come here.....she doesn't come here though now”*

**Maisie, Paid Urban Service**

During observations, people accessing Blended services used a mixture of transport (community bus, family transport, taxis, car share). This was unsettling as people were leaving the service as fieldwork notes demonstrates

*At the end of the session families arrived earlier to collect clients than taxis and community transport. This caused confusion with one client quite distressed that she didn't know how she was getting home. Staff were unable to offer reassurance as different family members collected each session. The coming and going of other clients caused further distress until her family arrived "who will look after me if nobody comes". Another client was very confused whether the taxi was booked and if it had been Paid for. Staff did not get involved in this process as it was viewed that clients using the service should be able to manage their money.*

#### ***Field note, Blended Service***

The above example also demonstrates the lack of interaction between the services and the family, discussed in chapter 9.

### **8.4. Food**

As discussed in chapter 6 there were differences in the food provision by service type. Clients discussed food provision in terms of quality, respite whilst maintaining independence and accommodating their individual needs. However, for many these aspects of the food provision was secondary to the welcome and interaction that it was linked to.

*"I've gotta give praise to the helpers and I've got to give praise to the cook they've got its brilliant, she's lovely and she really....you*

*can't fault her meal...you get a full meal.... Even before I sit down another lady comes down and goes.. toast and a cup of tea"*

**Norman , Voluntary Royal Service**

*I must admit I do love the chips so mostly I have the egg and chips because I love that but I normally eat small..... but today I'll have that lovely salmon so I decided I'd have that today.*

**Anne, Blended Urban Service**

The meal provision provided respite from cooking a meal at home referred to by both participants and carers (see section 9.4.3)

*It's great fun and someone else has to cook me lunch (laughter)  
and all the rest of it..... I just enjoy being waited on (laughter)*

**Val, Blended Urban Service**

Male participants referred to maintaining their independence through cooking, using the day care as a strategy to prevent the loss of independence.

*"I like, I like my own cooking and although the cooking here is probably better than my cooking its er, I don't want to get soft you know"*

**David, Voluntary Urban Service**

*"Yes I think its important to keep ...it'd be so easy to sit down and let somebody else do it for me er but I don't want to do that, I want to be able to live my life as normal as possible but as independent as possible"*

**James, Paid Urban Service**

In terms of long term conditions (LTCs), there was evidence of services adapting menus or providing alternatives for people's dietary requirements or personal preferences.

*"Well you know the morning, they make it special cos I don't want butter on...that's cos I'm cutting down and I've lost a stone and a half....."*

***Maisie, Paid Urban Service***

*"Oh the meals are good, I am diabetic and always want to eat small because I'm not a big eater"*

***Ruth, Paid Urban Service***

## **8.5 Activities**

Interviews revealed a difference in how clients discussed the activities that were linked to service type. As clients discussed day care the majority referred to company and being out of their home. However, clients attending rural Voluntary services discussed the range of activities. This section will give an overview of the activities that all clients talked about, with the last section highlighting the differences across service type.

The rural Voluntary service had a variety of activities. Clients were unaware until they arrived what the timetable of activities would be that day.

*"And you have something in the morning then you have this lovely lunch and a cup of tea in the morning, then you have say the artist all morning or whatever and then you have a lovely two course lunch and then you might have entertainment or whatever, say with the harp in the afternoon, so it's so varied"*

### ***Elisabeth , Voluntary Rural Service***

As discussed in chapter 6 the types of activities can be categorised into various types. This chapter discusses the activities described by the clients attending the day care.

#### **8.5.1. Individual**

Clients commented on the availability of resources to enable them to access activities that they can do on their own within the centre or when at home. The quote below refers to reading

*“there was a library you know and I used to read a lot an awful lot, so well, you go there and you can sit there.....Well here I’m calling it the library and it was a couple of seats but with plenty there”*

### ***Emily, Voluntary Rural Service***

#### **8.5.2 One to one activities**

Clients referred to conversation and companionship with other day care attendees on a one to one basis as part of the reason for attending.

*“Well we keep in touch with life really (laughing)...so catching up”.....*

### ***Pam, Blended Urban Service***

*“That you’ve got people to talk to similar to you all”*

### ***Edith, Paid Urban Service***

*“enjoy talking to .....he used to be a forrester. So that’s a little something we have in common. You know it’s an affinity there you know. You know he lost his wife a few years ago so he gets a bit*

*tearful at times, but he's alright you know, he's alright, so I like him.....We have a natter and I don't think either of us are great conversationalists like but I like that"*

**David, Voluntary Urban Service**

*They don't let you just sit there, they come and talk to you, found it hard to talk to the ladies. But this chap he comes, they come the two of them as a click...we've started talking but luckily they realised I was struggling with a bit of welsh so they converse in English, so that suited me down to the ground.*

**Norman, Voluntary Rural Service**

*A lady attended the centre and passed a poem to a gentleman. He was very touched and emotional. He explained that the lady had read it at the centre and this was a copy of it for him to keep. The client had written the poem herself and each line of the poem started with a letter from the name of the centre. He was recently bereaved and the poem had comforted him. A gentleman next to him explained that on the way home on the bus the driver had stopped to allow the client to take some cuttings for the lady from his garden that she liked. In return she had brought him a copy of the poem*

**Field Note, Poppy Centre**

**8.5.3 Small group activities**

**i) Collaboration & stimulation (games, puzzles, quizzes)**

In Blended and Voluntary services clients would join into smaller groups and undertake activities that required collaboration or competition. Cognitive

games or quizzes would usually take place with small teams competing, rather than put individuals under pressure. Clients enjoyed the interaction during these activities.

*"I find it very rewarding and it's er there's a lot of competition if you like, you want to be able to answer a question, and questions you know. I find it er very stimulating.... Oh the quizzes...I really do..I love them...and the exercise too...they're very gentle but that suits me 'cos I have bad knees"*

***Anne, Blended Urban Service***

*"Well the person in charge, always asks us what we like to do. So er you know I always play scrabble or play cards or do the crossword, like I can join in so if there aren't enough people to play scrabble or I just go and join in"*

***Eric, Paid Blended Service***

In section 6.5.5 people with dementia attending the day service was discussed. At one of the Blended services a lady continued to use the service although the dementia was quite advanced. She had been with the service for a few years and was settled with no mobility issues. The volunteers leading activities, as per the observation below meant that during cognitive games, she was an active member of the group due to the approach taken to deliver the quiz.

*The quiz was delivered so that group members were in pairs. Rather than shout out an answer a question would be given to each pair in turn, allowing the pair to discuss. A client with advancing*

*dementia some mornings would become confused on arrival thinking she was dropping off her carer took great excitement at taking part in the group. A volunteer paired with her and then broke the question down into smaller parts to prompt the correct answer. The client was ecstatic every time they managed to get a point “who’d have thought I’d know that”!. [to compare with the Paid service whereby the quiz is delivered to the whole group over a microphone would have been too confusing].*

## **ii) Creative, contribution**

As mentioned in section 6.8 Paid staff services did not tend to arrange the groups into smaller teams for activities. However, for creative activities clients at the Snowdrop centre could access sessions taking part in another part of the centre for a small fee (see chapter 6), whereas the lack of creative craft sessions was highlighted as a negative for clients at the Sunflower Paid service.

*Well perhaps making like birthday cards and things, we don’t do as much as that now.*

### ***Edith, Paid Urban Service***

Section 6.4 discusses the space available to enable services to provide various activities. Observations at the above centre took place whilst the service delivered a short painting session for clients.

*There was lots of waiting around with nothing happening, clients very quiet in the room and then staff arrived with craft activities. As the service is restricted most of the week to one room, there was*



*delays as staff set up activities and then removed activities  
[compared at services with more rooms, volunteers or staff can  
prepare activities whilst other activities ongoing]*

***Fieldwork note, Paid Urban Service***

However at the Voluntary services and some Blended services the activities that enabled people create and contribute were highlighted by clients.

*Then there's another lady that comes and she's what they call an artist really. She brings all the paraphernalia with her, the erm and the paperwork and what well...we sit there and one of the helpers said to me....you're going to have to do...'cos we're next door to the chapel said you're going to paint the chapel. And it was all new to me, it was sketching..what....so I had a go at this chapel and I did such a good job of it that's its hanging up in the chapel*

***Norman, Voluntary Rural Service***

*it was the three things, painting on glass, painting on the wooden things and something else and I have a little thing like a flower with a peg on the top and you can put paper on and stuff.*

***Kate, Blended Urban Service***

*Knitting Well gosh I used to do so much more, I used to knit and then I used to sew and I don't do either now...well I do a bit of knitting. Well I'm doing the tops for the bottles at the moment but not today because she doesn't come today.*

***Pam, Blended Urban Service***

The activities that enabled clients to produce creative form were discussed favourably in terms of achievements but also in the Poppy centre in terms of contribution to the community as the quote below illustrates.

*she had us transplanting and then, we'd put all these flowers and put them in tubs and I said what are you going to do with these now. "oh Im going to put them round the outside" she said now next week we're going to do vegetables and I said where in the hell are you going to put vegetables? You watch and see she said to me and fair play she put them all along one wall and she put the canes and for our lunch we've had runner beans from the garden...tomatoes...*

***Norman, Voluntary Rural Service***

This element of the Poppy activities was described as a replacement for solitary life and loss of ability due to LTCs. The types of activities were referred to in terms of enriching and form of self expression. This is discussed in more detail in section 8.7.4

**8.5.4 Larger group interaction – for example cognitive or physical stimulation**

Paid services had more whole group activities rather than breaking the group into smaller teams. Sunflower Paid service did break the group up but only for outings. See section 6.8.

**i) Passive activities**

The role of the client during group activities could be categorised as passive or active. For example clients at the Sunflower Paid service talked about

concerts and performances that they enjoyed. However, their role in the activity was passive observer being entertained.

*I like the ones in the park they were very nice, I liked the music and the people were nice to you*

***Edith, Paid Urban Service***

Alternately visiting speakers attended the Poppy rural Voluntary service with their talks aimed at promoting participant interaction.

*you heard there were three men in our group and even they their memory was going but once people was talking about something, he said well I remember when I was going to school you know what happened*

***Emily, Voluntary Rural Services***

**ii) Engaging activities**

The types of activities were explored during interviews in terms of whether or not the enjoyment or participation in activities reflected preference or hobbies prior to commencing at the centre. Even if the activity was not of preference to the individual, participation and interaction during the whole group activity was appreciated.

*“Now I’m not mad on bingo but everyone else does (laughter). I tried it once.....It does my head in! (Laughter), I’ve tried it you know in the past years ago and I’ve thought you know its not that bad but It is. Its mind numbing, it is (laughter), mind numbing” (and on exercise class) “Its er a (whispers) bit boring (laughter) but you know its er people get going, together”*

### ***David, Voluntary Urban Service***

As discussed in chapter 6, group exercises took place but there was the added benefit of moving about to get to the centre rather than staying in the house was also highlighted.

*So really I've got to walk, from here to the other side of the road cos he daren't block off the main route in that sense (transport)*

### ***Norman, Voluntary Rural Service***

In the Sunflower Paid service centre a session led by a local church, encouraging participation, interaction and discussion from the group proved to be a distraction from pain for an amputee at the centre.

*A client, an amputee was struggling with phantom pain and apologised before the session started as she had been intermittently jumping and crying out during the earlier part of the morning. Throughout the session, the client only partially jumped and took part in the session much more comfortable than when sitting waiting for the session to start.*

### ***Fieldwork note, Paid Urban Service***

#### **8.5.5. Community interaction –**

##### **i) mixing with other groups**

The lack of creative activities observed in Paid services discussed in chapter 6, was negated by activities available in the adjoining community centre that clients could access.

*"They do take them over to see if they want to go in and some of them stop in and some won't because they can play dominos in*

*there, they can paint, knit and crochet and they'll show 'em what to do. They're a nice group*

***Ruth, Paid Urban Service***

*"there's four or five of us go through, yeah, you know that lady, she's not so good this morning but she said she wants to watch the dancing so it'll get us out of here and we'll go through"*

***Joan, Paid Urban Service***

Staff in Paid staff services raised the challenge of organising community events in section 6.8.5. Further evidence was observed during fieldwork at a Blended service.

*The service ran a day service and a lunch club and brought the two services together for a national event, with a lunch and musical entertainment. Despite being encouraged to mix with seating arrangements the two services sat with their own groups. The luncheon club clients were more mobile and helped themselves to food. Many left after eating "the music is not our age group, it's all the war songs". The service encouraged interaction but little took place.*

***Field notes, Blended Rural service***

**ii) Group outings to the wider community**

The group outings to the community were only a regular occurrence at the Sunflower Paid service. However, clients did not speak about the activities favourably during the interviews.

*No I don't it's the same place all the time over in the farm,*

***Edith, Paid Urban Service***

*Some days we don't do anything we just sit there and its just boring (how often?) well it used to be Monday and Tuesday regular but its not so bad now you see cos they take half of them out for dinner you know a pub lunch,*

***Maisie, Paid Urban Service***

Therefore the empowerment of client choice discussed by staff in section 6.8.4 was not evident in the interviews with clients. The activities were highlighted by those completing the participant satisfaction questionnaires. The following section will discuss further, the aspects of the group discussed by clients.

## **8.6 Group Dynamics**

The following section discusses the role of the wider group highlighted by clients during their interviews. Some clients stated that the negative association of aging of attending an older persons group was one aspect of the service that had to be reconciled before they started.

*"Well when I first started coming.....I didn't want to come (laughing)...I said what down there, it's for old people and I'm not old. Laughing so anyway when I did come down I enjoyed it".*

***Ruth, Paid Urban Service***

*Well you come like and I mean I know I'm nearly 92 but I don't feel 92 and I thought what are you on about you're an old woman yourself (laughter). And after I gave myself a talking to I sort of warmed to it, and I like coming now.*

***Joan, Paid Urban Service***

The staff were credited with providing a safe and welcoming atmosphere within the group.

*“you know it’s so nice the people all who come here are so nice but the staff, the atmosphere everything is perfect.....I find the whole atmosphere here is very comforting, you sense it as you walk through the door”*

**Anne, Blended Urban Service**

*“Well Diane who runs everything, well she is very very good and she can spot things that are going wrong and what not and she can put it right..she’s very astute like that.....And you feel totally safe with her and everybody. Nobody shouts at you”.*

**Val, Blended Urban Service**

*“and being as we’re all getting on you enjoy the same things more or less you know you er you have the same interest*

**Emily, Voluntary Rural Service**

However the lack of small group activities within the Sunflower Paid service seemed to prevent relationships forming.

*“they said different things come on but it doesn’t seem to happen like.....a bunch that never opened their mouth from when they come til they went home I found it a bit boring coming you know just sitting there like and er I don’t know and I don’t know why anyone would want to talk to me .....And there wasn’t much happening you know and they put the telly on now and again but you get enough of that of a night I found it a bit boring coming you know just sitting there*

*like and er I don't know and I don't know why anyone would want to talk to me..... I get a bit fed up just sitting, whether there's something going on, it doesn't have to be spectacular like, they had Bread (TV Show) the other day and we've all seen it".*

**Mary, Paid Urban Service**

On other occasions the lack of interaction with other group members created a barrier to future attendance. If clients did not have similar interests or connect socially with other members, attendance would not continue.

*I've been once on a Tuesday er but I prefer going because I know the people on a Thursday*

**Emily, Voluntary Rural Service**

It was common, when participants were trying to describe why they liked the group they were currently attending, they used examples from previous groups or centres that they hadn't liked. The issues around group dynamics are relevant here to take into account client's needs.

Lack of variety of activities was highlighted as an issue.

*"there was this older chap there with this guitar...and he used to play it's a long way to bloody Tipperary four times a day (laughing) and that was in the morning, never mind the afternoon (laughing) "*

**Bob, Paid Blended Service**

*"Yeah and they had videos and they were showing a film that was of no interest to anybody there really you know ...."*

**Jack, Voluntary Rural Service**



The types of long terms conditions in relation to the dementia was highlighted by a number of clients, discussed in section 8.8.4.

This was also the case for clients who were more mobile attending services with people who had more severe mobility needs. In the case below, the centre ran 2 sessions however the group had different people with higher level of mobility needs attending on one of the days.

*“now you know I went to the other one on the Thursday and I wasn’t happy there... I think that there the people are a little bit er more disabled if you like and so I told them that I didn’t want to continue there with that....*

***Anne, Blended Urban Service***

There was evidence of camaraderie between clients supporting each other through difficult symptoms associated with their long term conditions (LTCs).

*A client was struggling to walk due to pain and mobility issues.....”I can’t do this much longer”.....another client started shouting “don’t think like that or it’ll get worse”...followed by lots of encouragement as she walked back “see you can....just take your time....stop that sort of talk”.*

***Fieldwork notes, Paid urban service***

At Blended and Voluntary services, the camaraderie was extended between group members, with clients taking on responsibility for other clients. This was not observed in Paid services, where motivational support or physical support would be provided by Paid staff only.

*A male client had been in hospital where concerns were raised that his poor mobility meant that he may not be safe living in his own home. Another client supported him walking to the toilet and later to an activity with lots of verbal encouragement “take your time”, “see you can do it”, you can show em”.*

***Fieldwork note, Voluntary rural service***

Whilst group cohesion was a common occurrence at the centre, this particular observation also illustrated the challenge for volunteers. At the Paid centre at times two staff were observed supporting clients to walk within the centre. However, at the Voluntary centre, the age of the volunteers was higher and they were unable to physically support the client in the above observation. Therefore, another client volunteered to provide support. At the same centre, emotional support was provided to a client who was 103. The client spent a large amount of time in a wheelchair and was restricted by sight and hearing loss and throughout the day different members of the group took turns to sit with her and chat, later providing support for quizzes.

This dual role was observed in Blended services also, as the fieldnote below demonstrates.

*Clients helped pour drinks, pass around snacks, set up equipment for activities supporting the volunteers without being asked [comparison also evident in Voluntary service and other Blended service]*

***Fieldwork note, Blended urban service,***

As discussed in section 6.9.2 in Blended and Voluntary services there was evidence of older people who were carers attending the day service with and without the person they cared for.

*It benefits me definitely because I don't actually have to join in, I don't have to, I didn't one day I just stayed in the kitchen and talk to the volunteers there, they're ever so kind there.*

***Theresa, Voluntary Rural Service***

This dual role of clients attending the services, presented blurred roles within the day centre between those of clients and volunteers.

**8.7 Impact**

Clients articulated the impact attending the service had on their quality of life.

The impact ranged from reducing loneliness, providing a change of scene, companionship throughout the day, increasing confidence and reducing anxiety. However two types of transcripts were evident and associated with the type of service. The majority of interviewees raised the theme of companionship or company when asked what aspect of day care they valued. However people attending the rural Voluntary service would talk about the types of activities they took part in. People attending other services would also highlight particular activities but it would not be the first thing discussed.

**8.7.1 Reduce Loneliness**

The first quote demonstrates that despite relocating to live with family, isolation is still a problem for the client. However, the experience of attending the centre has promoted confidence to attend other community activities. The client visited a large group in the past but didn't go back as found it too noisy and experienced a high level of anxiety.

*“And it’s lovely .....but it’s very lonely..... and my daughter and son in law, they’re out at work obviously all day it’s er ....the house is a little bit off the road and so you don’t see ...you see people passing the gate at a distance but I never see anybody.....but every single day, every single evening my daughter comes over to check I’m ok...and has a chat and her husband pops in every so often but er you still very much alone because they’re so busy.....”“And there is a bit of me now saying.....now maybe I should give it a try again (another group)...I feel so happy when I’m here*

***Anne, Blended Urban Service***

A housebound client who had mentioned earlier that their isolation had resulted in them being fearful of people, described how the centre had enabled him to look forward.

*I’d miss it here..you see (wife) calls me every morning and she says it’s Wednesday and she’ll say “where we going tomorrow?”(sing song voice) and say...we’re going to day centre (sing song voice) and she knows (laughter) I mean the first thing I do now when I go home is put my £2.50 in for next weeks’ meal, all ready for next week.*

***James, Blended Urban Service***

**8.7.2 Companionship**

As previously discussed in section 7.5.4, satisfaction survey 44% of people reported their lives were better due to the interaction and 21% reported their lives were better due to the company. Companionship was a common theme during interviews with clients.

*“Well, being in company, being in the company of people, well if I was by myself I wouldn’t be here long. If I was erm you know I’ve always been a person mixing with people.*

***Emily, Voluntary Rural Service***

*Oh the companionship, definitely everyone is just lovely*

***Val, Blended Urban Service***

*Well its meeting people, meeting new friends every week every Tuesday,*

***Eric, Blended Urban Service***

*It’s the interaction. Now I read a lot at home, so I can can, you know you can read forever but and some people do as well.....I like a bit of television and a bit of reading. I like to mix it up you know. Variety is the spice of life.*

***David, Voluntary Urban Service***

However, for some the companionship did not relate to the interaction as the comments from the participant satisfaction survey show in response to “in what way is your life better, the same or worse”? The client was contented to be in the company of others but did not need to interact or have conversation.

*“I have company now, even not talking to, someone to listen to, I’m happy when I’m here”.*

***James, Paid Urban Service***

### **8.7.3 Increased confidence**

Clients reflected on their improved self confidence by attending the group.

The affiliation with continued choice in their lives was connected to independence as illustrated by the last two quotes.

*“I’m not very good....well at least I thought I wasn’t very good with people....watch people whatever was going on and I do still find myself watching and not doing and you know and not being as open (laughs) but I’m definitely learning to change and to chat like I’m chatting to you”*

**Val, Blended Urban Service**

*“I have more faith in myself...but I kept losing faith when people kept saying you MUST have this and you MUST have this carer and that and I’ve always been an independent person and if someone says you must do something, it’s like a red rag to the bull, no way will I do it.”*

*James, Paid Urban Service*

*“Well when I come in here of course I am completely relaxed. I don’t have to do anything, I don’t have to think of anything, I can do just what I want to do rather than what I am told or asked to, so that makes a difference”*

**Kate, Blended Urban Service**

#### **8.7.4 Enriching activities**

As discussed above a central theme of transcripts from people attending rural Voluntary services was their description of the range of activities they took part in at the centre. There was no set routine to the activities and there were a combination of group activities with the common theme of production. Whether this was a craft creation or co-constructing a story with their counterparts and group facilitator. One participant described the activities in association with self expression:

*as you come into your house things get smaller and smaller and there's no opportunity for you, you know to express yourself, that's what of the things you see at the centre, even there's some of the people there that are very quiet you know ..... they'll come out of some beautiful things you know and it's an opportunity for them*

and whilst talking about conversations initiated by a speaker or group leader the same client added:

*things like that and it enriches your life you know just to have...it's like reading a book you know....*

***Emily, Voluntary Rural***

The latter part of the quote reveals the sensory benefits of face to face contact. Where sensory issues may restrict people accessing visual forms of stimulation, the manner in which the session is run at the centre promotes creation in terms of dialogue through memories or stimulated by the group leader's topic for the day.

In the Paid staff Sunflower service, the session run by the community church also ensured clients that had difficulty communicating could take part. The group leader lead a discussion, during which more able clients joined in and contributed but at the same time an item was passed around for those quieter members of the group to think about the item and understand better what was being discussed. One member had capacity to understand but struggled to speak, using only very small phrases accompanied by lots of gesticulation to communicate. The observation below demonstrates the delivery method enabled a connection for the client, despite difficulties in communication.

*During the session the church leader asked people to think about something they cherish. Those that were able to communicate were sitting together and started a discussion. The leader called on people to share with the rest of the group. A sudden shout from the client only able to say small phrases interrupted the discussion. "I cherish you", he shouted gesticulating at the church leader, he then pointed to the group and shouted again "I cherish you". The group applauded him and a number of staff were emotional at his sudden response.*

#### **Field Note Observation, Paid Urban Service**

In section 6.3.4, it was mentioned that the above church delivers the session in the day centre to alleviate the sense of loss or exclusion people may experience attending traditional services in the community designed for families. The above observation demonstrated that the session delivered in the centre enabled the client, who had severe communication difficulties, to



engage and interact in this way, whereby the traditional service would not have encouraged this.

## **8.8 Service Provision**

### **8.8.1 Challenges for Voluntary services**

Service users praised staff and volunteers but there was also an acknowledgement of the difficulty of running groups with volunteers. Dismayed by the lack of groups available for older people one client had attempted to set up her own group but this was unsuccessful.

*Some surgeons have decided that that's a good activity for people who have problems with their hands (colouring books and art). So I bought a few books and I thought I would try and get a few people here to do it but I did try on a Wednesday afternoon. And several afternoons I would sit in this room and nobody would come!*

***Kate Blended Urban***

A number of clients used the day care as other groups were unreliable at the centre despite being advertised as a centre for older people. The day service would not get cancelled however, other groups at the centre would.

*Shouldn't say this really but things happen here and you can hear about them or not and nobody takes nobody notices or whatever. Then somebody has a meeting or there's a notice about a meeting and then you next thing you hear about it's been cancelled.*

***Dot, Blended Urban Services***

Another client worried about the sustainability of Voluntary groups as she had experience of running a group, however her deteriorating health meant that it had stopped operating due to a lack of volunteers.

*oh it broke my heart and I prayed. And I asked them, please would somebody take it but ... Yes and they were crying the last day you know and yet they were fine in the group but nobody would take it up and for me it was heart breaking and for me I was very, very sorry.*

**Emily, Voluntary Rural**

### **8.8.2 Impact by service type**

This section will initially discuss the impact of the service for rural clients and then by service type. Challenges for clients who were attending the rural services were not evident in transcripts as was anticipated. In fact with regards to the distance to travel to the centre as highlighted in chapter 7, one client surmised that it was a fact of village life that travel was expected.

*Now there's not enough interest in this village so I don't mind travelling 40 minutes to the centre, erm I have to drive 30 minutes to get shopping, I know there's a local shop but if I want to buy clothes or something you're talking about an hours drive so it doesn't matter..... if you live in this village you have to travel*

**Theresa, Voluntary Rural**

Clients attending rural services did raise the issue of culture more often than other services. The Welsh language was spoken in the centre and based in a chapel, some clients had sought out a specific centre that fitted with their cultural needs as well.

Section 7.5.4 outlined the positive and negative aspects of day care services that clients reported using the satisfaction questionnaire after 12 weeks attendance. As discussed 44% of people stated that their lives had improved since attending due to the interaction and company, with 18% mentioning the activities that they had taken part in. There was no trend between service type when analysing the satisfaction questionnaire however there was a trend discovered in the transcripts of people attending rural centres. Clients talked in depth about the activities that they enjoyed in addition to the types activities they experienced.

*The author who came, I was beside myself, I had to facetime my grandchild I was so pleased*

**Norah, Voluntary Rural Service**

### **8.8.3 Client needs and aspirations**

A dominant theme in client transcripts and completed satisfaction surveys was the need for company and social interaction. There was limited reference to clients well being or independence, despite services highlighting this as a central function of the service. During data collection, I was concerned the clients may have a low aspiration of what they required from the service. The satisfaction survey (section 7.5.4) completed by the 73 participants who attended for 12 weeks, was positively favourable. I therefore wondered due to the difference in the narrative whether there was a difference between service users' expectations and what services aimed to deliver. However, during fieldwork a client discussing plans outside of day service provided an alternative view regarding this issue.

*A small group discussing the week ahead, one client mentioned she was looking forward to travelling to visit her sister for the weekend who lived in another area of the UK. When asked what they had planned she said “nothing, I’m just going to sit and hold her hand.....I’m so excited to see her....I can’t wait”.*

***Fieldwork note, Blended Service,***

It was this observation that provided insight into the issue around service expectation. The participant, rather than lacking aspiration regarding the level of service valued the close connections. A contracting of social worlds due to multiple loss (bereavement, illness) meant that interaction was sought and valued by the client. It provided insight into the social world that cherished connectedness rather than ‘doing’. Conceptually the age group is referred to in terms of physical and cognitive ability with services designed to reduced immobility and loneliness whereby an existential need to connect may be more important to this client group.

**8.8.4 Dementia specific services**

As mentioned above, to exemplify aspects of the service they liked, some clients provided examples that they didn’t enjoy at previous services that they had attended. For some clients with a diagnosis of dementia but in the early stages, referral to dementia specific services caused problems due to behaviour of people with more advanced types of dementia.

*.... I was going to come out and the door came smack (gestures hit him in the face). I just managed to step back a bit, so I just you know, I give him a dirty look.....you know let it go. But then later he did the same, so I reversed my stick you know and I said, I’m gonna*

*knock your bloody teeth out cos you know he nearly had me the first time”.*

### ***Bob, Blended Urban Service***

This correlates with the findings gained during observations in section 6.5.5. exemplifying staff had experience of clients joining the service from a dementia specific service to attend the more generic day service.

## **8.9 Summary**

This chapter provides evidence from client interviews, observations and satisfaction surveys regarding the impact that the service has from the client's point of view. Clients did not refer to one aspect of crisis as suggested in the literature but cumulating events such as bereavement and disability. This presents day care as separate entity to other respite care models associated with acute conditions.

Clients valued the activities that took place with the impact of the service falling into particular themes. Client's valued companionship, cognitive activities, enriching activities and sessions that promoted connectedness. It was also felt that a reduction in loneliness and improved confidence for some was achieved. Client's who were in the early stages of dementia, with experience of diagnosis specific services valued the approach taken in generic services in preference to dementia specific services.

The culmination of loss discussed in this chapter, raises the question of when support is most beneficial for clients experiencing change in their circumstance and status. This issue and the fact client's usually had had no experience of

the activity that they took part in suggests that the day care service is in a unique position to introduce clients to a new activity in a non- threatening environment. This will be discussed further in Chapter 10. The following chapter provides findings from carer's of clients attending day care services. It presents the results of data collected by both quantitative and qualitative methods from the perspective of family carers.

## **9. Carers Findings (Qualitative and Quantitative).**

### **9.1. Introduction**

This chapter draws on data collected from carers who took part in the study. 16 carers took part in the quantitative aspect of the study and six carers took part in the qualitative interviews. This number of carers involved was less than anticipated and can be attributed to three reasons. As discussed in section 5 participants with carers were asked if they would give consent for their carer, a third of all clients did not have carers. Those that did have carers three quarters did not give consent for their carer to be approached, citing that they did not wish to add to their carer's current burden of workload. For those carers that did consent to take part in the study, the follow up questionnaires were not returned. Those that took part in the interviews were carers that were present at the centres when observations were undertaken, demonstrating how the observations transformed the research from an anonymous type of study and increasing participation.

Despite the lack of carers taking part in the study, it should be highlighted that the systematic review established that half of the studies looked at the impact of day care on carers. Therefore whilst carers' experiences are beneficial to the overall study, the priority was to understand the impact from the perspective of the clients. This chapter presents the findings from the quantitative questionnaire followed by the findings from the qualitative data obtained from interviews.

Chapter 6 and 8 highlighting the emerging theme of older people as carers either attending the day centre for respite away from the person they cared for

or older people attending together with one as the carer or both caring for each other. This chapter solely relates to the carers who do not attend the centres as participants. The needs of carers including those utilising services at the day centre will be discussed further in section 10.5.

## **9.2 Adult Carers Quality of Life Questionnaire (AC-QoI)**

The following section provides findings from the completed questionnaires given to carers who volunteered to take part in the study. 15 Carers completed questionnaires at baseline, with one carer joining the study at the first follow up time point of 6 weeks (see section 9.1, for previous discussion regarding this). The table below illustrates the completed rate for the three time points.

The lack of responses for the follow up do not enable detailed analysis of outcomes to be undertaken. However, baseline data gives a better understanding of the needs of carers using day care, see Table 28.

### **9.2.1 Ac-QoI Results**

The mean total score for the Ac-QoI was 68.2 indicating a mid-range quality of life for cares who participated. Responses ranged from 49-100 with no carers indicating that they had a low quality of life. The table below illustrates the results for the mean for each domain and the percentage of results by quality of life range.



**Table 27: AcQoI timepoints completion**

	Baseline Only	2 timepoints completed	3 timepoints completed
Number of Questionnaires completed	4	6	5

**Table 28: AcQoI baseline responses by domain**

Domain	Mean	Low QoL %	Mid QoL %	High QoL %
Support for Caring	7.5 (±3.7)	40	33	27
Caring Choice	6.2(±4)	53	33	14
Caring Stress	9.3(±3.4)	20	40	40
Money Matters	9.2(±3)	13	47	40
Personal Growth	7.1(±3.1)	20	73	7
Sense of Value	7.9(±3.9)	27	53	20
Ability to Care	10.7(±1.8)	0	47	53
Carer Satisfaction	10.2(±1.7)	0	67	33

**Table 29 – comparing Sample Carers baseline with National survey of 3387 carers.**

Report Population (3387)	Sample (carers)
66% 45-64	47%
18% >65	53%
80% female and 20% male	80% female and 20% male
Caring for >5 years = 66%	Caring for >5 years = 40%
Caring for >50 hours per week = 64%	Caring for > 50 hrs per week 66%

**Table 30: Carer Pseudonym identity for qualitative interviews**

Name	Age	Service	Caring role
Angela	68	Poppy	2 years caring for husband in own home, interviewed with husband
Christine	73	Poppy	3 years caring for husband in own, interviewed separately from husband
Kathleen	55	Birch	2 months caring for father in own home, interviewed separately from father
Margaret	68	Poppy	8 years caring for mother in mother's home, interviewed separately from mother
Maureen	58	Blackthorn	6 years caring for father in law in own home, interviewed separately from father in law
Susan	75	Poppy	2 years caring for husband in own home, interviewed with husband

Table 28, illustrates that the Caring Choice domain is the domain with the highest proportion of respondents with a low reported quality of life, followed by the Support For Caring domain. Highlighting the types of needs that carers using day care services require support with. In terms of the domains, Ability to Care and Carer Satisfaction, both did not have any respondents in the low quality of life range. In fact the Ability to Care domain had the highest proportion of respondents in the high quality of life range.

### **9.3 Carer Baseline**

At baseline 60 participants attending day care reported that they had a carer either living with them or living elsewhere (see chapter 7). 26 people reported that their carer did not live with them. 34 people had a carer who lived with them. 16 carers did take part in this aspect of the study. 14 of the carers that responded lived with the person they cared for. It should be noted that carers were from the rural service illustrating the relationship between the participant carer and the service when comparing other services.

#### **9.3.1 Aging, Gender & Caring**

The age of carers participating in the study ranged from 42 years to 88 years with a sample mean of 64 years. 40% were between the ages of 45 and 64 whilst just half (53%) were over the age of 65 years of age. It was interesting to note that those carers utilising Paid staff services, all were under the age of 65 whilst those accessing Voluntary services all apart from one carer were over the age of 65. 80% of the carers taking part in the study were female and 20% male. The carers in the study reported that they had been a carer on average for 7 years, ranging from 2 months to 30 years. 40% of carers had

been a carer for more than 5 years. 66% carers in the study sample spent more than 50 hours per week caring.

Comparing carers' results with the 'In sickness and in health' report (Carers UK, 2012) found that of 3387 carers 18% were over the age of 65 years of age. Therefore, for those people attending day care, there was a higher proportion of people over the age of 65. 80% of the carers taking part in the study were female and 20% male, replicating the findings from the national survey

40% of carers had been a carer for more than 5 years, less than the national survey of 66% (however the national survey includes parent carers of children with additional needs, which may be from birth). 66% Carers in the study sample spent more than 50 hours per week caring, a similar figure to the national survey.

The data above demonstrates that caring for people with LTC can go on for long periods prior to accessing day care. It could be suggested that accessing day care takes place once the burden increases for families or isolation increases. Therefore, the support people require is not triggered right away as maybe the case with a sudden acute period of illness.

The number of Carers taking part in the interview aspect of the study was higher in the rural areas reflecting findings from chapter 7 regarding a higher proportion of clients who had family member living at home. Those Clients had less support from carers not living with them compared with urban services.

## 9.4 Qualitative Findings

Carers took part in the semi structured interviews following the client's twelve weeks attendance at day care. As with the participants in chapter 8, a pseudonym table has been developed to ensure anonymity during the reporting of the findings.

### 9.4.1 Access

There was a general awareness from families that there was a rationing of services for this population group. There was an acknowledgement that finding the right service that the families felt connected to, in terms of its philosophy and outlook.

*I think it's a shame that...that nowadays more little places like this aren't open. I think it's a shame because it's an awful lot of people....it's that break...isn't it...*

***Susan, Poppy Voluntary Centre***

*She came here (Voluntary Service Representative) and the way she was explaining the centre, from the minute she started talking about it seemed homely, it seemed the type of life we actually live. Its seemed quiet life really, you know just work and chapel and that sort of thing, what we're, like family life*

***Angela, Poppy Volunteer Centre***

The carer's utilising the service for respite highlighted the issues with the time and frequency of provision. The service run by volunteers closed during holiday periods due to volunteers' commitments outside of the service. The summer break in particular families found difficult.

*So when the driver..what's his name he said ...enjoy your holiday...I was depressed (laughter). Holiday I thought to myself...cos it was closing...holiday ...it was shut for what was it 5 weeks*

***Susan, Poppy Voluntary Centre***

*She misses it terribly, she couldn't wait to get back there and now I don't know what will happen over the summer.*

***Margaret, Poppy Voluntary Centre***

For working carers who were transporting relatives to day care, the starting time and lengths of sessions prevented them remaining in their current working environment.

*It starts at 930 but from a practical point of view being in education, 930 is too late to start work. And by the time you get to work it would be 10am so it'd be too late to start*

***Kathleen, Beech A & B, Blended Service***

#### **9.4.2 Long Term Conditions**

The nature of long term conditions (LTCs) was raised by carers and the confidence that families had in the service ability to support their relatives. Stable periods interspersed with bouts of illness are common in the population group and day care provided peace of mind for carers when using day care for respite. The carer below highlights the stress of sudden illness for carers of people with multiple LTCs.

*and if he was taken ill, I know it sounds awful but if he was taken ill its somebody else's responsibility. If he wasn't well there and he*

*was ....and the volunteers had to ring an ambulance or something  
and I feel that all the time*

***Susan, Poppy Voluntary Centre***

However lack of Paid staff and service criteria at Voluntary services were highlighted by one family due to the needs arising from LTCs. Despite the carer mentioning earlier in the project that the service enabled her to still do activities with her husband, in the interview she commented that this had arisen due to his health condition.

*Well I started going because I had to stay with him I had no option,  
but now I'm staying there I enjoy what is going on.....for what it  
involves somebody wearing a catheter it only needs opening a tap  
sort of thing but because it is a distance from here and it's so  
situated by the time I've got there I may as well stay.*

***Angela, Voluntary Rural Service***

The combined issue of the distance to travel to services (discussed in section 7.2.10) in rural areas and the restricted support volunteers can give with regards to continence issues is highlighted above.

Illness and loss associated with the aging process proved difficult for carers to judge appropriately what services were most suitable. Sudden bouts of acute illness may end with loss of functioning or recovery, therefore it was not always clear what level of support should be sought.

*And I just said what is out there?... you know..it was never very  
clear, ...but the kind of summary from previous social services was  
that perhaps he wasn't bad enough to go into a nursing*

*home.....its about trying to establish how poorly he really is, what his level is... Is it as the hospital thought? Is the accident really traumatic that with my mum dying is he in shock? Will he improve?. Now he has really improved since where he was in May. He's definitely better, he's over his injuries and he's definitely less confused, like what the hell is going on, which he was*

**Kathleen Beech A&B**

Carers of people with mobility problems referred to the need for day care due to the restrictions long terms conditions had brought.

*I sometimes get fed up...er sometimes...yes I do...and I feel quite down about things because I just feel through no fault of his own really..I just feel that our life has come to a stop and at times and at times I can feel like a prisoner here...er I do...*

**Susan, Poppy Voluntary Centre**

However, a lack of understanding was evident by some relative as to the types of activities that would be achievable due to disabilities.

*we tried to find him things to do but at 91 what can they do?*

**Maureen, Blackthorn Blended Service**

*But it's impossible to cater for all the types of needs of the elderly. Because you know they have sight problems, hearing problems, mobility problems.*

**Margaret, Poppy Voluntary Service**

The quotes above reflect a difference in approach to the needs of disabled elderly population when considered against the needs of disabled children and adults. It could be suggested that the presumed loss of function in later life promotes a less inclusive approach to support these needs when compared with younger people with disabilities.

The face to face aspect of day care was highlighted with carers suggesting that engagement and discussion facilitated for the age group broke through the issues that sensory loss brought people with LTCs.

*I was thinking of this is a bit weird because she's just reading from a book but actually they were all really engaged in this and really listening and my dad was listening "oh, Oh " and they're the generation that listen to the radio, they're the generation that don't use computers, they're the generation that are much more tuned into people's voices I think.*

**Kathleen Blackthorn Blended Service**

*I used to take her there to see her friend, but seeing her every week now is wonderful because what is difficult for people of my mother's age is that their hearing goes. And whereas the phone used to be company for people, you can chat to people on the phone, that gets more difficult. You can't talk on the phone like you used to.*

**Margaret Poppy Voluntary Service**

In recent times there has been an increase in schemes targeting older people within their own homes such as befriending or older people's helpline. This



perspective illustrates the value of day care in facilitating relationships beyond the home when traditional methods are more difficult due to sensory loss.

#### **9.4.3 Impact of day care**

Carer's observed improved physical functioning through both the motivation to get ready for the day, the mobility needed to leave the house and exercise sessions whilst at the day centre. This was an advantage to individuals accessing a support service within the community rather than home visits.

*And it's doing him good, before he went to the centre his mobility, well his mobility has been bad for a long time erm but its helping his mobility going there, because he's got to walk out from here to the front door and sometimes because the dial a ride bus can't park because of the cars parked, so he has to walk with his zimmer, very slowly and I do the same when he comes back at tea time.....So in that sense he is having exercise....but otherwise he would sit here er apart from going to A to B, ,he would sit here....from the time he gets up in the morning to the time he goes to bed at night.*

**Susan, Poppy Centre**

*I wanted my husband to have somewhere to go or to have something to do because I feel that if he is at home he will drop off to sleep, but by going somewhere having something to do it keeps his mind occupied.*

**Christine, Poppy Centre**

Maintaining mobility by accessing the centre could be combined with accessing the transport provided, to enable families to increase the respite time provided.

*But we find if we walk him in the morning it gets him mobile more and he comes back on the bus so we don't have to go and get him so we get that extra half an hour on our own really*

***Kathleen, Blackthorn Blended Service***

Carers spoke of the mental stimulation company and activities could provide for people who were losing their ability to undertake their usual activities due to the nature of the LTCs. The quotes below illustrate the need and the impact.

*For the simple reason because he has got dementia but he does like to be busy. He won't sit in a chair, he won't read a book. He doesn't like watching the TV obviously because he can't always take it in. So it's not stimulating him. And we felt if we did a day care or something where he could stimulate his mind maybe it would help him remember things.*

*He's also meeting people, having conversations with other people that he's not getting at home.....because there's only a limited amount we can say to each other.... it helps mentally that he's more alert...*

***Kathleen, Blackthorn Blended centre.***

The difficulty of maintaining friendships and relationships due to the sensory loss that LTCs may bring was highlighted. The day care service being face to

face in a supported environment ensured that existing friendships could be nurtured whilst creating new relationships.

*but seeing her every week now is wonderful because what is difficult for people of my mother's age is that their hearing goes. And whereas the phone used to be company for people, you can chat to people on the phone, that gets more difficult. You can't talk on the phone like you used to..... when she comes home she is a totally different person, it has lifted her spirits, she is on the phone to me. She wanted to say what she's done, who was there and what was said and she wants to talk about it...*

**Margaret, Poppy Volunteer Centre**

A number of clients relocated to live with relatives and day care provided them with a chance to reconnect with existing relationships prior their role as carers.

*And it also gives us a break to do the things that we want to do because we can't sit down and have a conversation because we have to involve him in the conversation*

**Maureen, Blackthorn Blended Service**

For carers not living with the person they care for it was stressed how their role in managing two homes put pressure on them.

*I do take care of everything but if you live in your own house you have house insurance you have electric, you have gas bills, you have bills, there is house maintenance there are all sorts of things to do. That's the advantage of people living in sheltered*

*accommodation or housing that belongs to housing associations or agencies, they don't have to worry about that.*

**Margaret, Poppy Voluntary Service**

The meal provided at the centre also gave the carer a break in the evening from cooking.

*"I also (laughing) know he's had a meal so I don't cook him a proper meal when we get home, I do him sandwiches and stuff and there's that thing you know so we have sandwiches type tea so I don't have to cook a proper meal which I do because I feel I should*

**Kathleen, Carer daughter**

**9.4.4 Barrier to day care**

As discussed in section 8.6, clients provided examples of previous groups as a way of illustrating what they hadn't liked compared to what they did like in the current group. Some carers provided the same sort of description. Early diagnosis of dementia meant that some families were directed to dementia specific provision however with their current needs the service had not been suitable. The group dynamic with clients with more severe needs had restricted the level of interaction and stimulation that clients may have. There was also a barrier for men in terms of some groups with low membership from men.

*With that one he was fine when he first went, it was great and then they seemed to get more and more dementia patients that were worse than him, so when he tried to have a conversation it wasn't happening*

### **Maureen, Blackthorn Blended Service**

*she wouldn't go and she knew some of the people that were there and she said no no and that they had dementia so she didn't want to go there and the words she used were "I'm too good for there", not too good too posh, but too good mentally,*

### **Margaret, Birch Blended Service**

*But he didn't like that one for the simple reason because it was all women. So he basically didn't have....basically anyone to talk to about sport.*

### **Maureen Blackthorn Blended Service**

#### **9.4.5 Service Type**

Despite the lack of involvement from carers utilising Paid staff services in the qualitative interview, one family accessed a Blended service and a Paid staff service not taking part in the study. The flexible approach of Blended and Voluntary services perceived by the family supported earlier findings in chapter (services).

*because of that I think the quality is better than people who are employed to provide day care and it's not because oh, how can I describe it.....sometimes there's volunteers there's more things going on and I think that's because the people who are doing it because the people who are doing it are perhaps motivated to be more creative and that perhaps if you're employed you get that thing about being employed where you start to do it as a job, do you see the difference? It's interesting isn't it if the quality is different isn't because it's run by volunteers, because there seems to be*

*more people coming in from outside. I mean there was a pianist here a few weeks ago playing some fantastic music on the piano and it's multisensory.*

***Kathleen, Birch A&B***

The carer then went onto to provide an analogy using early years education to exemplify the difference they had found using both Blended services and Paid staff services.

*now that's the sort of thing you get at play group isn't it, banging on drums you know but at nursery school there's a regimented thing, I mean it's very different now I'm not saying the quality isn't there [Paid staff service] but it is very indicative of day care you might get at a residential home.*

***Kathleen Birch, A & B***

## **9.5 Summary**

This chapter explored the impact of day care from the perspective of the carer. It established that carers within day care spent long amounts of time caring for their family member, due to the nature of LTCs. Day care provided respite from their caring duties and also from the anxiety associated with their condition. Evidence was presented using the quantitative data sources from the AcQoL and the qualitative interviews with carers. As described in the section 9.1, the number of carers taking part in the study was lower than anticipated. The reasons for this related to the lack of carers for a third of clients, lack of consent given by clients to contact the carers and how the services interacted with carers.

This chapter brings to a close the findings from the various data sources. The following chapter discusses the findings in more detail, exemplifying where points merge or conflict between data sources arise.

## **10. Findings and Conclusion**

### **10.1 Introduction**

This chapter will initially provide discussion points relating to the findings presented in previous chapters, with each objective then discussed in turn.

The strengths and limitations of the study will then be presented, with the contribution this study makes highlighted before findings are summarised and a final conclusion provided. Summarised findings to be discussed in this chapter are highlighted in Table 31 accompanied by the identification of the source of the analysis from which the findings were derived.

### **10.2 Findings Discussion**

To examine the provision of day care from the staff's perspective in chapter six, provides not only the context for later chapters but demonstrates how the configuration of services affects the management of LTCs and ability to provide particular activities. It provides greater context with regard to participants' reality (Lincoln and Guba, 1985). Chapter three reported that literature pertaining to day service research did not report on the service models (Manthorpe 2014). Chapter six described the services with additional attention given to the support provided for LTCs.

Observations at the centres and interviews with staff revealed that recent changes to referral processes not only meant that how people accessed services changed but the management of their long terms conditions was also affected. Blended, Voluntary and rural services had to introduce their own informal assessments in the absence of formal assessments. On the basis of the formal assessments there was a cumulative benefit for clients who met the



**Table 31 – Summary of Findings**

Findings	Data Source / Analysis
<p>There was a statistically significant association between those clients reporting no change or a reduction in EQ5D3L problems between baseline and 12 weeks follow up. Clients with a higher number of LTCs (mean number 4.4 LTC) reported no change or a reduction in the number of problems. Those with a lower number of LTCs (mean number 3.6 LTC) reported an increase in the number of EQ5D3L problems at 12 weeks (<math>p=0.04</math>). This suggests further exploration could establish what type of support could be provided for those with lower number of LTCs possibly adapting to challenges associated with multiple long term conditions.</p>	<p>EQ5D3L quantitative data</p>
<p>A significantly higher proportion of clients attending paid day care services reported suffering from a self care problem at 6 week follow up (46% compared to 32% of blended service clients and only 10% of voluntary service users, <math>p=0.02</math>). There were no other statistical differences between outcomes for clients across service type and geographical area.</p>	<p>EQ5D3L quantitative data</p>
<p>The number of EQ5D3L problems reported by clients attending voluntary day care services reduced between baseline and 12 weeks, whilst the number of those attending paid and blended services increased.</p>	<p>EQ5D3L quantitative data</p>
<p>The proportion of clients attending voluntary services that reported a reduction in anxiety was greater than at paid staff services although this did not reach statistical significance.</p>	<p>Quantitative data – De Jong Giervald loneliness questionnaire</p>
<p>There were no statistical significant differences in loneliness outcomes between clients attending different service types or geographical areas between baseline and 12 weeks. However, total loneliness scores increased in paid staff services but decreased at blended and voluntary services. This was due to a reduction in emotional loneliness at blended and voluntary services not observed at paid staff services.</p>	<p>Quantitative data – De Jong Giervald loneliness questionnaire</p>
<p>The likelihood of ‘any improvement’ in outcome revealed that those attending blended services were over twice as likely to experience a reduction in de jong loneliness scores between baseline and follow up (<math>OR=2.01</math>, 95% CI 0.65-</p>	<p>Observations, staff, client and carer interviews.</p>

<p>6.22, <math>p=0.23</math>). Older people attending voluntary services also had a raised likelihood of reporting reduced loneliness compared to paid staff services (OR=2.46, 95% CI 0.74-8.26).</p> <p>The configuration of paid staff services was advantageous to the management of LTCs. Accessible transport, streamlined referral systems, trained staff, accessible devices, supportive client aids, disabled-friendly accommodation, equipment and furniture enabled clients to attend paid staff services more consistently. The absence of these components presented challenges for blended and voluntary services.</p> <p>Blended and Voluntary services provided flexibility for those clients attending with their carers or were carers themselves. Activities that promoted self-worth and a sense of purpose provided opportunities for connections within the group and the wider community to be developed. There was also evidence of this in the rural service.</p> <p>The provision of blended, voluntary and rural services was dependent on other services in order to function in terms of space, transport, food and provision of activities. Despite the fragmentation of services favourable outcomes were demonstrated therefore further support and development within the services would deliver a more sustainable model for clients with LTCs</p> <p>The decision to access day care services did not stem from one particular trigger but a cumulative effect of combined scenarios resulting in loss such as illness, disability, bereavement or relocation. The respite model referred to in the literature pertaining to day care does not reflect the model observed during this study for older people with long term conditions.</p> <p>There were no statistically significant differences between clients attending blended and voluntary services when compared with paid staff services, despite the latter service requiring clients to meet a needs threshold in order to access the service. In rural services there was a statistically significant difference between the number of LTCs reported by clients at baseline and those attending urban services (<math>R=5.2LTC</math>, <math>U=4.2LTC</math>, <math>p=0.04</math>).</p> <p>Arthritis was the most frequently reported LTC across all service types. However, a higher proportion of clients attending paid staff services reported LTCs such as early stage dementia and stroke than in voluntary services. This suggests that the diagnosis reported may play a part in meeting the needs threshold to access paid staff services.</p>	<p>Observations, staff, client and carer interviews.</p> <p>Observations, staff, client and carer interviews</p> <p>Observations, staff, client and carer interviews</p> <p>Quantitative data – LTC questionnaire</p> <p>Quantitative data – LTC questionnaire</p> <p>Staff, client and carer interviews</p>
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<p>There was evidence of clients in the early stages of dementia opting to attend generic day care services rather than dementia specific services that they were referred to.</p> <p>At baseline there was a statistically significant difference in the negative response of clients attending blended service compared to paid staff and voluntary services responding to the question “there are plenty of people I can rely on when I have problems”.</p> <p>Clients attending voluntary services and rural services faced statistically significant longer journeys to access day care services compared with paid staff or urban services (Paid=2 miles, Blended=2.11 miles, Voluntary=5.84 miles P=0.001 and Urban = 2.21 miles, Rural=8.31miles p0.001).</p> <p>At baseline clients attending blended services were older than those attending paid staff and voluntary services, reaching a statistically significant threshold (p 80.9, B 84.7, 80.4 p=0.04).</p> <p>Baseline data revealed that those accessing the service were all white, with older people from ethnic minorities not recruited into this study. In blended and volunteer lead services within this study there were very low numbers of ethnic minorities in the surrounding areas. However, for Paid staff services there were higher ethnic diversity close to the national average.</p> <p>There was strong evidence at 12 weeks that clients who continued to attend day care reported high level of satisfaction. 86% of participants reported that their life since starting the service was better or much better.</p> <p>Clients highlighted that meeting new people and interacting with people were the main benefits of attending day care. Enjoyment of collaborative activities were a common theme but secondary to the social element of day care.</p>	<p>Quantitative data – De Jong Giervald loneliness questionnaire</p> <p>Quantitative data – demographic questionnaire</p> <p>Quantitative data – demographic questionnaire</p> <p>Quantitative data – demographic questionnaire</p> <p>Quantitative data – demographic questionnaire</p> <p>Quantitative data – +12 weeks satisfaction questionnaire</p> <p>Quantitative data – +12 weeks satisfaction questionnaire</p>
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needs threshold in the form of adaptations, aids and devices to support those with sensory loss and communication difficulties. Those attending Paid staff services had aids that alleviated the loss that accompanied their disability, but other aids were not observed in Blended or Voluntary services. Paid staff services and staff at Blended services also demonstrated knowledge of moving and handling for people with frailty. Therefore, the formal assessment clients attending Paid staff services undertook, resulted in them accessing wider support for their LTCs.

Transport did not just provide convenient access to the centre, it provided greater flexibility for the service in terms of accessing external events and managing LTCs. Services that accessed community transport highlighted the lack of escorts for people with LTCs. The lack of flexibility and dedication to the service in urban areas meant that the service did not meet the needs of people using day care. Charmaz (1997) suggested a feature of chronic illness, was the illness itself became predictable but the symptoms and episodes of poor health did not. With illness a common occurrence the service was limited as to how they could support people appropriately without their own transport. In the rural area the community transport was dedicated to the service for the day, however it was still restricted by the distance it could collect clients from. People living outside the designated area still had to rely on family or friends to either take them to the centre or to an area that the bus collected from. Policy makers and transport providers target resources where they are most likely to be effective (Broome, 2010). Streamlining of resources during the course of this study revealed access issues in particular for clients from rural areas.

Day services provided a wider monitoring function for people who attended, such as prompting medication, observing fluid and food intake, liaising with families regarding continence issues, paying attention to money management, dressing and personal hygiene. All this demonstrated added value for people attending the day care service. The services that had an input in the collection of people from their own homes, either by an accessible bus service or taxis, could also monitor people whilst they were in the community. From a safeguarding point of view communication between services provided information to enable day care to further support people whilst at the centre. Clients could also be signposted to other services for additional support when required.

The day care services taking part in the study were generic services designed to support people who had a range of needs. Observations demonstrated the evolving needs of people using the service such as people with dementia and people under the age of 65 with similar needs due to issues such as learning disabilities, drugs or alcohol misuse. The presence of people who were carers of older adults with special needs or health problems at the centre and those who attended with the people they cared for demonstrated the circumstances behind the changing configuration of day care services.

A key aim of the National Dementia Strategy (UK Government, 2009) is to improve early diagnosis of dementia so that people can be supported to overcome problems and improve their quality of life. Staff and volunteers highlighted the presence of people with dementia using the services, both in the early stages and more advanced stages of the disease. There was evidence that those with an early diagnosis did access dementia specific

services however, they withdrew from services due to group dynamics at the centres. The staff felt that generic services were able to accommodate clients with early stage dementia.

Blended and Voluntary services were limited to the types of support they could provide people due to training and ratio of staff or volunteers. Therefore, people struggling with feeding or continence issues who otherwise could benefit from the service would be signposted to another service. The nature of the space available to the service varied from services that can access adjacent rooms for activities to stand alone services functioning in one room. Limited space for some services impeded the opportunity to move around throughout the day.

Integration of services in the literature predominantly refers to the close working relationships between health and social care. The study highlighted the various levels of integration between services to enable the entity that is day care to exist. This was observed not only in the form of transport as discussed but also in the form of food provision, facilities and the provision of activities. Paid services had the provision for personal care, in one service personal care was only to be accessed in emergencies as day care was not deemed to be a domiciliary service. Paid services benefitted not only from knowledge about the client's needs upon arrival but one service also shared the IT system where communication to other services could be provided and gleaned.

Activities and food were delivered differently at Paid, Blended and Voluntary services. Staff had to deliver activities around breaks and shifts. This was not the case at Blended or Voluntary services with staff and volunteers joining

clients for lunch. This difference appeared to be related to hierarchy, evident between staff and clients in Paid staff services. In Blended and Voluntary services the roles between client and volunteers were blurred with clients taking on supporting roles for each other and during provision of food and delivery of activities.

The evidence provided through observations and staff interviews demonstrates the relationship between day care service configuration and service provision. It provides detailed information regarding the configuration of the types of day care services engaged with the project. In addition to the areas of focus such as transport, food and activities the observations also established the relevance of space, contractual relationships between the day care provider and other agencies and the extent of integration and interaction within the group and with other groups.

To consider findings from chapter seven, it is understood that the population is aging. However, the increasing demographic is also a changing demographic with the proportion of older men, people from black and ethnic minorities and people aged 85 years and older, predicted to increase in the near future. In the past day care has been traditionally utilised predominantly by women. The findings revealed that whilst the ratio of women was greater to men, Voluntary and rural services had a more equitable split between men and women accessing the service. There is a lack of reporting of user's age in day care literature (Manthorpe, 2014). People attending Blended services were significantly older than those attending Voluntary and Paid staff services ( $p=0.04$ ). Those attending rural services were on average older (83.3) than in urban areas (81.8) although this was not significant. This provides a greater

understanding for practice as to the types of people accessing day care. The average age of the sample was over 80 years, with those attending Blended services close to the older old category of 85 years.

Clients accessing the service were all white, with clients from ethnic minorities not accessing the services engaged with the study. Whilst there were some low levels of ethnic minorities in the surrounding areas of Blended and Voluntary service, for Paid staff services this reason did not apply. Local demographic information suggested a level of ethnic minorities close to the national average however those starting at the day centres during the course of recruitment were only white. This raises the question as to why older people from ethnic minorities are absent from the service.

The number of people from ethnic minorities is predicted to rise from 170,000 in 2006 to 1.9 million in 2051 (Runnymede, 2012). However, to consider the proportion of the population in the surrounding area of Snowdrop service reveals a different picture. It also raises the question whether the lack any BME clients reveals a barrier for people accessing service or are day care services not designed or marketed to meet clients needs? It has been suggested that the assumption that older people from BME have stronger support networks and may not want to access such support services is unfounded (Katbamna et al 2004). Whilst the issue has been addressed in some areas with specialised services targeting specific BME communities, there are concerns that this may prevent such access issues being addressed by the mainstream service (Butt J. & Mirza K, 1996). It has been suggested that there is a failure of many services to market themselves effectively people from ethnic minority backgrounds (Manthorpe et al, 2014). An opposing view



is that many ethnic minorities view seeking help with shame and guilt around failure of the family (Patel & Traynor, 2006). However it is reported the discourse around the view that ethnic minorities will look after their own is too simple (Gandhi & bowers 2008).

Considering specifically day care services, it has been reported that day service is the preferred service used by BME clients as they did not necessitate overnight stays and staff did not need to access people in their homes (Jewson et al 2003 and Manthorpe, 2014). Therefore, the complete absence of any BME users recruited into the study highlighted a need for further research into this area.

The inverse care law suggests that services are provided in areas with less need. There was no evidence of this, as the proportion of people living in deprived areas was highest in Paid staff services ( $p=0.02$ ) suggesting that services are being targeted appropriately in terms of deprivation.

Baseline data provided insight into issues around access for older people using day care services. The distance travelled by clients of day care varied significantly between services with those attending Voluntary services travelling further than those at Paid staff and Blended services and those attending rural service travelled the greater distance ( $p=0.001$ ). In terms of support to access the service, there was a higher proportion of people attending Paid services who reported that they did have a carer but the carer did not live with them. In urban services this reached statistical significance when compared with rural areas ( $p=0.03$ ). This demonstrates further barriers for people accessing day care in rural areas.

Chapter six provided evidence that those who attended Paid services were supported with equipment and devices, implying that those who passed the needs threshold may also access wider services for support more appropriately. Data revealed that a lower proportion of people attending Paid staff services who reported pain when compared with Blended and Voluntary services. This could suggest that accessing Paid services may be associated with greater access to management of LTCs via medication. This issue could also be applied to support for anxiety and depression. A higher proportion of people attending Voluntary services reported problems with anxiety and depression, compared to Paid and Blended services.

It was expected that as those attending Paid staff services did so after a needs assessment that reached the required needs threshold, the number of LTCs reported would be higher in Paid staff services. However, this was not the case demonstrating that charities and Voluntary groups are managing the same level of need when considering multiple LTCs. Those at rural services reported a statistically significantly higher number of long terms conditions when compared with urban services ( $p=0.04$ ). To explore the types of conditions by service a pattern emerges that suggests that the diagnosis may be a factor in accessing the Paid staff services. Those reporting an increase in EQ5D3L problems at 12 weeks had a lower number of LTCs. Those reporting a decrease in EQ5D3L problems at 12 weeks had a significantly higher number of LTCs. This suggests that day care was more effective for people with a greater number of conditions. Is this due to people further on in the process of adapting to their disability or as Corbin (1998) suggest,

evidence of people deciding to live with their illness whereas those earlier on in this process are not getting as much from day care.

The most common LTCs reported in Paid staff services were similar to those in Blended services. Conditions such as arthritis, dementia and stroke were the most dominant reported conditions in rural areas, however there was a greater proportion of people reporting cancer in rural areas compared with urban areas. With regards to stroke and dementia diagnosis, it could be suggested that those accessing Paid staff services may meet the needs threshold due to the issues around personal care that such a diagnosis brings in terms of the associated disability.

However, analysis of the baseline EQ5D3L data demonstrated that the reported problems with self-care was higher at Voluntary services and lower at Paid staff services. There was a greater proportion of people using rural services that reported problems with self-care demonstrating a trend compared with those in urban areas but the trend did not reach statistical significance ( $p=0.09$ ).

Chapter six highlighted that staff felt increasingly that there were more people with dementia accessing day care services. Observations also revealed the Paid staff services facilities enabled people with dementia who may “wander” to be managed safely in the centre due to security and staff ratios. The quantitative data revealed the prevalence of dementia in all services ranged from between a third of new participants in Voluntary services to half of new participants in Paid staff services. All participants reporting dementia were in the early stages of the condition. During observations there was evidence that clients with early stage dementia had left dementia specific services.

Therefore, the combination of data relating to this issue suggests further research around the needs of early stage dementia clients and if services require additional training and support to meet their needs.

To consider access issues in relation to attrition rates, 21 clients were lost to follow up resulting in an attrition rate of 22%. Previous studies with this population group have lower recruitment rates and higher attrition follow up. For example, De Bruin et al (2011) reported an attrition rate of 40% from a sample of 88 participants; Drees et al (2004) reported a 31% attrition rate from a sample of 80 participants and Higgins et al (2005) reported a 43% attrition rate from a sample of 37 participants.

Therefore, attrition is expected in this clients group 8% of clients recruited into the study were lost to follow up as they entered nursing home or residential care. All of these clients were based with Snowdrop Paid staff service. Chapter six, revealed that staff at the Paid services felt that this was due to issues for the carer outside of the centre rather than the level of need for the client. Documentary evidence states that the lack of adaptable housing in the relevant area is a key issue for the local area with a higher proportion of people moving to institutional care for this reason (Rodgers 2011).

In terms of the level of support people felt they had, a lower proportion of people attending Blended services reported that they did not have people to rely on. A higher proportion of people in Paid staff services and Voluntary services did not feel that they had people that they could rely on ( $p=0.04$ ). There was a reduction in social loneliness scores across all three service types. However total loneliness scores increased in Paid services but decreased in Blended and Voluntary services. This was due to the increase

in emotional loneliness at Paid staff services. However, emotional loneliness scale also decreased in Blended and Voluntary services. Therefore, analysis of loneliness scores demonstrated that volunteer provision is effective in producing favourable outcomes for people experiencing both emotional and social loneliness. There was a trend that a reduction of loneliness was more favourable for women attending services ( $p=0.11$ ) but this did not reach statistical significance.

The pattern was similar when analysing changes in outcomes for clients attending rural services. There was a reduction in total loneliness and social loneliness scores at twelve weeks for clients attending both urban and rural services. Whilst there was a slight decrease in emotional loneliness scores at urban services, there was a greater observable reduction in emotional loneliness scores for those attending rural services over the first twelve weeks.

The satisfaction survey undertaken by those attending services at 12 weeks was predominantly favourable, indicating that irrespective of changes in outcomes, clients reported in their own words their high levels of satisfaction with the services they attended. There has been debate around the advancement of outcome based commissioning. It has been suggested that the strategy is not suitable for some public services (National Audit Office, 2015). There can be confusion between system level and individual outcomes (Hoong Sin, 2016). The results of the satisfaction survey in section 7.5.4 demonstrate the relevance of this issue. Responses from the satisfaction survey were overwhelmingly positive however using outcome based measures, revealed a differing rates of outcomes by service type and geographical area.

It should also be considered that the manner of the data collection, such as the self reported measures selected for this study bring this issue to the fore. Charmaz (1997) suggests that people experiencing illness may avoid acknowledging decline due to its effect on their individual identity. Therefore, the selection of the types of outcomes pertinent to the service and the way in which they are measured are central to the debate around outcome based commissioning. In some cases local authorities have engaged with users to reframe and define the outcomes most important to them, co defining what a successful service should look like (Hoong Sin, 2016).

Self-reported levels of LTCs were similar across all service types, demonstrating that Blended and Voluntary services are supporting clients with the same level of need when compared with Paid services. Clients attending rural services had statistically higher number of LTCs than clients attending urban services. The challenges to recruit clients from rural areas supported observations and feedback from staff that streamlined community transport services no longer served rural areas. Those accessing Paid staff services benefitted from accessible community transport that provided additional support for clients who experienced common bouts of illness.

The referral systems and client information available to Paid staff services upon commencement with the organisation enabled appropriate support for the relevant long term condition (LTC). Training, policy, secure facilities and staff to client ratios observed in Paid staff services enabled those requiring support for physical, cognitive and personal care issues to be supported appropriately as symptoms and conditions progressed. Despite this the proportion of favourable outcomes in sections 7.6 was greater in Voluntary

and Blended services. However, satisfaction rates were high in all service type and geographical areas.

Statistical outcomes in section 7.5, revealed that whilst total loneliness scores reduced in Blended and Voluntary service they increased in Paid staff services. On closer inspection of the results it was revealed that all services demonstrated a reduction in social loneliness but a reduction in emotional loneliness was only observed in Blended and Voluntary services. Comparison of loneliness outcomes across urban and rural services demonstrated a greater proportional reduction in emotional loneliness at rural services. There was a greater reduction in the level of social loneliness for clients attending urban services.

The combined findings from chapter six and seven suggest that the approach of services may contribute to the outcomes for clients. Whilst social interaction in Paid staff services and urban services may support the reduction in social loneliness, the quality of those interactions through the delivery of activities may contribute in greater reduction in emotional loneliness levels at Blended Voluntary and rural services.

Chapter six and seven suggest there may be an association between the type of service delivery and types of outcomes that clients experience. Chapter eight explored this notion from the client's perspective. Clients reported experiencing change either due to physical or mental illness, declining cognitive ability or mobility, loss of close relationships and relocation to be nearer support networks. Charmaz (1997) suggests that illness and subsequent disability can force decline in expectation of the self that results in people relinquishing their former activities. This is consistent with the findings

in section 8.1 whereby one of the common triggers for clients' motivation to access the services was combined loss resulting in loss of ability to undertake their usual activities. LTCs put pressure on relationships with some clients referring to not wanting to burden their family members or withdrawing so that the outside became something to fear.

In the rural service there was evidence of client's welcoming the culture at the centre in terms of language. The literature suggests that carers and clients state the need for such services rather than services providing this automatically (McLeod, 2001). Client's valued that volunteers used their language with some client's not as fluent supported by other client's to engage through language.

It is suggested that people attempt to control their illness by trying to control their new emerging identity (Charmaz, 1997). They maximise their self-worth by trying to keep their illness in the background raising the idea that clients attending may be using activities to do this. The findings revealed that clients on many occasions had had no experience of the activity that they took part in. This raises the suggestion that the day care service is in a unique position to introduce clients to a new activity in a non- threatening environment. Considering the combined loss that clients reported in section 8.1, would an activity focussed session attracted somebody to attend? The generic nature of day care enables staff and volunteers to introduce activities that in turn return a sense of achievement and autonomy to the client. In activity dominant groups in the community the focus on the activity may be too challenging for somebody with the types of needs attending day care.



Common themes in the literature relate to illness shrinking worlds (Charmaz, 1997). This decrease in social connections may also force the client to focus on the aspect of interaction they value. One to one activities co-producing crafts, stories and competing in cognitive games were highlighted as valued activities at Blended and Voluntary services. In Voluntary services client's spoke of enrichment through the types of activity, about feeling safe. The service enabled clients who had reduced activities due to illness to partake in activities face to face with other people. They could draw on their existing ability, with another client or the group providing additional support. This combination of abilities, buffering their loss of function and achieving and contributing together to tasks.

In chapter 7, findings revealed that clients with less LTCs reported an increase in problems after 12 weeks attendance suggesting that more support may be required as they adapted to ongoing conditions. Findings in section 8.1 regarding the reasons to again raise the question as to when the most appropriate time is for services to step in to support clients. The cumulation of loss raises the question of when support is most beneficial for clients experiencing change in their circumstance and status.

In view of the difference between referral processes and transport processes available to services, this question is even more pertinent. Observations revealed benefits to clients attending services with accessible transport in terms of flexibility of service, physical access and accessibility of the wider external trips. Those without access to centre or community transport confirmed issues regarding asking family or friends for help. For those living in rural areas the distance travelled to access the centre often relied on family

members as community transport was limited to particular areas. The centres that were selected as they were expected to recruit from both urban and rural areas were unable to recruit people from rural areas. Therefore, considering the cumulative factors in triggering people's decision to access service or when to ask for help, this illustrates further barriers of services to be able to support people at the right time.

In Blended and Voluntary services activities were organised so that client's experienced interaction with other group members. This was not as common in interviews with staff/ volunteer or clients. Paid staff clients undertook activities as a whole group and discussed activities that were focussed around being entertained rather than engagement. Creative activities were a positive theme in the qualitative interviews but it must be remembered from chapter 6 that despite this, services sharing facilities with other organised stressed the challenges to providing such activities due to space and storage available. Whilst the Paid services gave clients the choice in terms of types of activities to take part in, the level of interaction within the group and the wider community was limited.

Whilst quantitative data in chapter seven suggests further inquiry is warranted as to the benefits associated with Blended and Voluntary services. Clients raised the issue of sustainability of the services due to the need for volunteers. Some clients had experience of trying to set up groups and to disengaging from the management of groups as disability increased.

Finally in chapter nine, the viewpoint of the carers is useful to understand the impact of day care on clients and their families. Charmaz (1997), stated that carers or an audience of the client play a role in the management of LTCs by

either allowing or obscuring the illness and acknowledging its temporality or not. Frank (1995), reported the chaos narrative is common during chronic illness, the common features being life not getting better with people feeling and revealing themselves to be vulnerable. In the midst of the chaos, people have no reflexive grasp on the situation. Evidence from the qualitative interviews demonstrated that day care provided distance in order for a carer experiencing chaos to reflect on improvements in her father's condition. The new normal was difficult to grasp but monitoring him at the centre provided clues as to what the new normal may be.

Two carers commented on the challenges of finding activities appropriate to the level of disability experienced by their family member. There was lack of understanding as to what activities would be appropriate for older people with LTCs, due to loss caused through disability, sensory loss and cognitive decline. Other carers spending time at the centre discussed how the day care provided opportunity for face to face relationships, activities that negated loss of ability were highlighted by carers that had observed the sessions at the centre. A greater understanding of this by carers could extend this support at home.

The data collated from the completed AcQoL Carers revealed that carers of people in Blended and Voluntary services were older than carers of people in Paid staff services. It has been reported that adequate provision of services for the care recipient is effective in supporting working carers to remain in employment (Pickard et al, 2015). The Care Act has legislated that carers should be supported to remain in work. The data although limited suggests that there may be some bias towards working families in accessing Paid staff

services or Paid staff services may be operating predominantly using a respite model. Qualitative interviews with carers revealed that the length of hours the Blended service was open, provided a barrier to continuing in employment. The day care session started later than the working day. People accessing rural services commented on the closures during holiday times, due to lack of volunteers. Thus whilst providing respite for carers it could not meet their needs to continue in employment if that was their aim.

The relationship between services and carers and the selected quantitative methods attributed to the challenges recruiting carers to the study. During observations structured programmes for carers, such as meeting centres in Holland described by Droes (2004) were not observed. Carers were supported with advice and signposting. Issues such as assessments, finances, welfare and pensions were referred onto other agencies. Continence advice was given and information about equipment. However, apart from that the support for carers was advice and respite.

Despite 16 carers consenting to take part in the study only a small number of follow up questionnaires were returned. In contrast to the support from day care services in promoting the study with clients, their relationship with carers was based more on a respite model and minimal contact with carers was observed. Therefore the anonymity of the researcher with carers may have resulted in lack of commitment to the project. The AcQoI measure has been developed with input from carers and used a variety of dimensions to fully reflect the caring role. However, with 40 items and administered via the postal service it may have appeared overwhelming and time consuming to

participating carers. Therefore it would be suggested a shortened measure would be used in future.

Charmaz discusses stresses on relationships and this adds to what was established in chapter 8, whereby the difficulties in some relationships due to the nature of the LTCs. Clients commented on attending day care to alleviate the burden on family members. Where clients had relocated to be with multiple family members the day care provided an opportunity for those family members to reconnect. When the length of time respite was available covered most of the day it was seen as more beneficial than short sessions available in the community. Where the service provided transport it increased the time the family had and eased the pressure of needing to collect from the centre.

Observations demonstrated an emerging theme of clients attending with their carer or partner in Blended and Voluntary services, highlighting an evolving need to be considered by day care services. Therefore, this chapter adds to the dominant respite literature of people attending using day care purely for respite. Patterns of attendance suggest those of working age more likely to access Paid Staff services whereas those with older carers access services provided by Blended and Voluntary services.

As discussed in section 7.7, in one local authority area it has been reported that housing stock cannot be adapted which presents challenges for people to age in place. Therefore, the support for families required is far wider than social care support. Carers may utilise day care services but once back in the community issues such as steps and stairs become too challenging for families to cope with and long term care becomes a necessity.

The following section now presents the discussion in relation to each study objective in turn.

### **10.3 Objective One: To determine if Paid staff models of day care provide better outcomes for older people with multiple long term conditions than Voluntary models.**

This section addresses the outcomes delivered at day care services, comparing evidence pertaining to services provided by Paid staff and services delivered or supported by volunteers (Voluntary and Blended services). This section will initially discuss the outcomes reported in chapter seven and then refer to evidence from chapter six, eight and nine to explore the results further.

As described in chapter seven, there were differences in outcomes for people attending day care provided by Paid staff, Blended and Voluntary services. There were positive outcomes for at least one of the services for each of the five domains apart from usual activities. However there were more favourable outcomes demonstrated at services provided by volunteers (Voluntary) or supported by volunteers (Blended). In addition all services reported an increase in the average VAS scores at 12 weeks. Paid staff services did provide favourable outcomes for anxiety and depression but as referenced in chapter 7, the proportion of clients attending Voluntary services that reported a reduction in anxiety was greater than at Paid staff services. Analysis of loneliness scores highlighted that whilst all services provided a reduction in social loneliness, only those provided or supported by volunteers saw a reduction in emotional loneliness.

As discussed earlier in the thesis (chapter six) the provision of services across the different service types varied. Observations established that the

configuration of Paid staff services was advantageous to the management of LTCs. For example accessible transport, streamlined referral systems, trained staff, accessible devices, supportive client aids, disabled-friendly accommodation, equipment and furniture all contributed to enable clients to attend consistently at the service. As illness is common amongst this population group, the aspects of Paid staff services discussed above provided added reassurance and support for clients when needed. The absence of some of these components at Blended and Voluntary services provided challenges when supporting clients with multiple LTCs. However, the results of outcomes for people attending Paid services were not as favourable as those attending Blended and Voluntary groups using the tools selected for this study.

To explore this further, the results for loneliness scores will be discussed in relation to data collected during observations. Favourable outcomes or reducing loneliness were demonstrated at 12 weeks by all service types however, Paid staff services did not demonstrate a reduction in emotional loneliness. Comparison of service types, using focused ethnography revealed differences in the facilitation and delivery of activities.

It was common for clients at Paid staff services to remain in one whole group with staff leading activities. There were opportunities at one centre for clients to join other activities taking place in another part of the centre (non-day care) and a small number of the group did choose to do this on occasion. In the other Paid staff service, the group would split whilst some used the centre transport to go out on trips. However, integration with other services was limited and interaction within the group was highlighted as lacking during the

client interviews. Connections to the community were also limited to being entertained as opposed to clients contributing to community projects.

Clients attending Blended and Voluntary services would break off into smaller groups for activities, with more interaction between the groups taking place. There was a greater choice for clients in terms of the types of activities they could undertake. Volunteers joined small groups to facilitate sessions rather than lead activities. In Voluntary services clients would contribute to the running of the day. Community projects were observed that would provide a sense of purpose and connection to the group, centre and wider community.

Therefore, despite the advantage of the more streamlined Paid staff services and access to more resources aimed at people with LTCs, it is suggested that the delivery of activities may be responsible for the promotion of more intimate relationships, promoting self worth and a sense of purpose.

The study used self-reported measures as the tool for data collection with the status of the client reported from their own viewpoint. It has been suggested that people with LTCs under-report their level of loss to avoid identifying with their reduced ability (Charmaz, 1997). The baseline data revealed a similar level of LTCs reported across all three service types. However, whilst attending the centres there was a higher number of clients using wheelchairs at the Paid centre. It may be that the EQ5D3L despite being selected for its brevity may not have provided enough range for level of mobility to be reflected across the services and a five point measure may have been more appropriate.



Despite the favourable results at Blended and Voluntary centres two themes from the findings demonstrate where further support of such services would benefit the clients using the service. At the Blended service the Steps project encouraging clients to increase their movement provided evidence of differences between Paid staff and Blended services in two. The Paid member of staff at the Blended organisation was trained in moving and handling to support people with mobility problems. Clients at the service moved with minimum support. A client commented during the Steps challenge that their fear of falling meant they didn't spend much time outside in their garden. The Steps challenge offered reassurance moving around the grounds of the day centre. As it was delivered from an aging friendly centre this also provided more confidence for clients. Paid staff services supported people as they moved, some one to one, others two to one. This presented more as a rehabilitation programme whereas at the Blended services it was a social event.

The Steps programme at the service revealed challenges to the service to collect the data required for the project. Staff and volunteers coordinating the project found this a new expectation for the service to monitor, document and report the progress required by the study funder. At Paid staff services there was a coordinator's role with responsibility for regular reporting for various projects that the service was involved with. Therefore, the approach to mobility issues at the two services were different due to the training of Paid staff and the regular use of data at the Paid service.

Findings revealed that at Blended and Voluntary services clients who were carers were using the day care service. This would take the form of them

using it for respite themselves, attending with the person they cared for, or a dyadic pairing where both clients cared for each other. This aspect of the day care user population is not recognised in the literature and was only observed in Blended and Voluntary services. Carers expressed the desire to undertake activities together. The day care service enabled them to do this with wider support from staff or volunteers whilst using the centre. Blended and Voluntary services used criteria related to continence and the ability to eat. Individual needs were met with food blended or cut up smaller for those that required it. Clients who attended with their partner or people that they cared for would sometimes support them at meal times. One client commented that in addition to spending time at the centre, they also stayed to assist with their partners medical needs.

It is important to note that despite favourable outcomes there are limits to the type of support Blended and Voluntary services are able to provide to people with LTCs. The fragmentation of associated services such as transport, create barriers for people accessing the services. Blended and Voluntary services can provide demonstrable positive outcomes, however further support and coordination of services would deliver a more sustainable model for clients with long terms conditions.

#### **10.4 Objective Two: Examine the differences in service models in rural and urban areas**

The second objective explored differences between rural and urban day care services. As outlined in section 5.5.3 a number of sites were expected to facilitate recruitment from both urban and rural areas. The sites were based in urban areas but people attended from surrounding rural areas. One site was

based in a rural area, therefore rural participants were guaranteed at that centre. Recruiting from rural areas became a challenge in the sites based in urban areas. This appeared to be a consequence of changes to transport systems. The sites were available to rural participants but participants were unable to access the service. The initial review of the data highlighted this and a contingency site (Ash) was established, again in a market town but with a surrounding rural area. The new participants that arrived were from close to the centre and again not the surrounding area. Therefore, this revealed the challenge not only for the study to recruit from rural areas but confirmed the access issue for people living in the rural areas.

However, clients in the rural centre (see section 8.8) did not discuss travelling or access to services as a particular issue. In fact one client did suggest that difficulty with travel was something people in rural communities had come to expect. Demographic data in chapter 7 revealed the length of journeys people undertook were significantly longer than people attending services in urban areas. When client comments regarding the length of the journey and cold journeys are combined, the challenges are illuminated. Despite the arrangement between the day centre and the community transport, the length of journeys are still significantly longer but this doesn't take into account the combined journeys on the bus. It also doesn't take into account that people from surrounding areas have to make their own arrangements to attend the centre.

The size of the group was similar to the numbers observed in the Blended services but the Voluntary service in the urban area was much larger. The urban Paid staff service was also a larger group, whilst the client group was

only slightly larger than the rural Voluntary service, the staff to client ratio made the group seem much larger. There was less interaction between clients in the Paid staff service as opposed to the rural areas. The size of the group in rural areas was observed to be beneficial to interaction. There was reciprocity observed in the rural service (see section 8.5.2.), this may have been related to the cultural similarities in the group such as common language. Clients attending rural services raised the issue of culture more often than those at other services.

The most obvious difference between services in urban and rural services was the frequency of service provision. The rural service was operational once per week and on another day once a fortnight. Clients suggested that this was sufficient as time was taken up with appointments, common amongst this population group.

Baseline data presented in sections 7.4.3 and 7.5.3 illustrated a trend whereby those attending rural day care services reported proportionally more problems with self-care. There were also a higher proportion of clients in rural services reporting problems when doing usual activities and pain/discomfort. Outcomes revealed reduced problems with anxiety and depression in both rural and urban services. Rural services demonstrated a reduction in reported problems of self-care and overall the total number of problems was also reduced in rural areas at twelve weeks. Further exploration of other rural services could reveal if this is common in other centres. Both urban and rural services demonstrated a reduced level of reported loneliness, however there was a greater reduction in the level of emotional loneliness in rural services and a greater reduction in the level of social loneliness in urban services.

### **10.5 Objective Three: Establish what aspect of day care provision attendees value**

This research study has explored this objective using client semi structured interviews and twelve week satisfaction surveys. This section will address the above objective demonstrating the aspects of day care that clients' value.

To consider initially, the findings from the client 12 week satisfaction survey. Section 7.5.4 highlighted that 98% of clients who completed the 12 week satisfaction survey reported that their life felt better or much better since attending the day centre. The follow up data does not take into account those that left the service, therefore a positive result would be expected from this questionnaire as people completing the survey had continued to attend.

The questionnaires demonstrated that clients predominantly valued the fact that day care enabled them to meet new people, interact with people and have company. The activities at the day centre were also a common theme but secondary to the social element of the service. The interviews enabled these themes to be explored in more detail.

Interviews highlighted companionship but this tended to be mentioned in contrast to not being isolated prior to starting with the centre. Attending the service enabled an opportunity for clients to partake in conversation they would not have otherwise. Whilst a small number of interviews mentioned friendships that had developed from attending the centre, the majority referred to general company and banter between the different members of the group. Friendships appeared to be built on similar experiences such as previous employment and common losses such as widowhood or physical disability.

Group banter was used as a description for the interaction taking place usually during activities. As mentioned in section 10.3 the composition of activities were highlighted more commonly in rural areas. Clients in other services did mention activities but in relation to collaboration during activities, usually cognitive games. It was common for disability causing physical or sensory loss, therefore solitary hobbies such as reading, writing or creative activities had become difficult. Collaboration with other client's provided a valued alternative. This did not necessarily relate to previous interests. Many client's highlighted that they were trying new activities for the first time and welcomed the stimulation provided by the service.

In addition to cognitive games, creative activities were a firm favourite. Craft sessions that resulted in a finished product were positively welcomed. This did not only take place solely within the day care group with members of Paid services accessing craft centres operating at the wider centre. Clients there also welcomed the opportunity to access affiliated sections at the centre, whether it be the market place in the Snowdrop centre or the book collection at the Poppy centre. More common in the Sunflower Paid staff service, due to how activities were provided was the entertainment taking place either in the centre or at external community events. It was more common for clients there to talk about the centre as a day out somewhere to visit as opposed somewhere for activity or companionship to take place.

The quality of the food was highlighted predominantly at the Voluntary services and one Blended service. The interaction associated with the food was beneficial and the opportunity it provided for people to have respite from food preparation in their own homes was valued. This suggested that the process

of interdependence was supported and valued at day care services whereby people can maintain their independence but with minimal support for daily tasks. Attending day care services for a meal during the day time, alleviated the need for this task in the evening. Many clients commented that something light and simple could be prepared at home.

The interviews revealed that the aspects of day care that client's valued such as company and activities were not difficult to deliver. However, as clients process the losses associated with ageing and their conditions, could it be suggested that client aspirations were lower than would be expected if they were in a different age group. Charmaz (1997) suggests that the acknowledgement of decline would affect damage to their self concept. Clients did not seem to have an expectation of what they wanted from the service prior to starting there. However, it was clear that day care clients valued companionship and interaction.

The service design of day care services for this client group, in the context of health related conditions, may be dominated by themes from the biomedical perspective of health for example maintaining physical function. Such services are situated within re-ablement models therefore the age group is referred to in terms of physical and cognitive ability. Therefore, caution should be taken when designing such services to avoid ignoring or excluding opportunities to connect. It was clear from data that this aspect of the day care service was sought after and may be more important to this client group in maintaining a quality of life.

## **10.6 Objective Four: Identify the drivers for people accessing Paid or Voluntary care**

This section will discuss the drivers for people accessing day care using the quantitative data obtained at baseline along with data from client and staff interviews. As discussed in section 8.1 during interviews there was no one specific trigger that was highlighted by clients as key to their decision in accessing a day care service. Issues from years earlier were discussed and revealed a cumulative effect that had led to clients retreating either due to disability or relationship loss. The comparison across services enabled the objective to be more specifically explored.

As previously discussed Paid staff services require clients to meet the needs threshold in order to access their services. Therefore, it was expected that the drivers to access particular services would revolve around this key issue. However, quantitative data suggests that the number of LTCs reported is relatively similar across Paid staff, Blended or Voluntary services. Clients in the rural service reported a significantly higher number of long terms conditions compared with clients in urban services. Therefore, the number of LTCs did not appear to be the trigger for particular services to be sought out by clients. This aspect of drivers to access services will be discussed in further detail at the end of the section.

Using baseline data, the proportion of clients who had carers not living with them was significantly higher in urban services compared with rural services. As the type of relationship between the client and carer was not collected, the only detail known are that these are family members that they do not live with. This could suggest that these carers may be adult children possibly still of



working age. However, rural services have a higher proportion of clients who are married suggesting that in rural services clients would need spouses to access the service, whereas in urban services this may not be the case. Of those carers who responded to the AcQoI, carers at Blended and Voluntary services were older than in Paid (under 65yrs) services. That again suggest that clients who were attending Paid services may be supported by working carers. How this relates to meeting carers needs is discussed further in section 10.5.

The distance travelled by people accessing day care service in rural areas was statistically further than those accessing urban day care services. The transport available in the rural services was restricted to particular areas so clients further afield relied on family or friends to attend or get to the location to meet the transport. In services that aim to support people from both urban and rural areas, the lack of transport reveals that people in rural areas are not attending the services. The lack of people from minority ethnic backgrounds attending the service suggest there may be different needs by this group either in terms of access or provision that are not currently met by day care. However, there is evidence in the rural centre that culture and language attracted clients to the service, travelling further to access Voluntary services rather than Paid staff services that did not meet their language needs.

Whilst outcomes revealed that female clients were more likely to achieve positive outcomes, most services had an equal balance of both genders in the centre, with only Blended services having a higher proportion of female clients, although this was not significant.

At first it was theorised that mobility problems may have been a driver in people reaching the needs threshold for Paid services. On closer inspection self reported problems did not support this and arthritis (causing mobility issues) was the most common condition across all services and not just Paid services. However, there was a higher proportion of people attending Paid day care services that had stroke, respiratory disease, dementia and neurological conditions. Therefore, it is suggested that the self care issues for personal care may be the driver for those accessing Paid staff services. The types of conditions also suggested that people with early stage of dementia accessed more generic older people's day care service. Qualitative data from staff, volunteers, clients and carers suggested that clients sought out generic services rather than recommended dementia services due to the stage of their condition.

#### **10.7 Objective Five: Investigate the types of carers' needs met by day care provision**

This study explored the needs of carers utilising the AcQoL questionnaires and interviews with carers. As discussed in chapter 9, in total just under two thirds of the sample stated that they had a carer. In order to recruit carers into the study, clients were required to give consent for me to contact their carer. The most common reason given for clients not permitting this was cited as not wanting to add to their carer's burden. Therefore, a quarter of carers consented to take part in the study.

There was a challenge however regarding the return of the questionnaires resulting in low follow up numbers over the first twelve weeks. It is suggested

that the AcQoI instrument with forty questions may have been too demanding for this client group and a shorter measure is recommended for future longitudinal studies.

However, baseline results provided some understanding of carers needs. The lowest quality of life domain related to caring choice. The systematic review revealed that over half of studies reviewed the impact of the day care services on carers with regards to the respite function of day care. Clients in Paid services raised attendance at the service as giving their carer time to have a break from caring responsibilities. Staff at both services stressed carer breakdown as the reason for referrals. As reported in section 9.3.1 carers at Blended and Voluntary services were older than in Paid staff services suggesting needs may be different by service.

Those carers that took part in the interviews all reported that the respite was their key need. One carer said that while in the midst of relocating her parent, the service offered support by signposting local services and understanding what needs her parent had.

As discussed in chapter 6, observational data revealed that clients who were also carers were utilising Blended, Voluntary and rural day care services. As previously mentioned, for a proportion of the carers they supported adult children with LTCs, for others they were carers attending to get a break from the person they cared for and some carers attended with the person they cared for. For these carers the Blended, Voluntary and rural service offered flexibility of criteria so that they too could attend and take part in activities. Clients did

not have to justify their level of need to attend. The dual identity of older people being clients is expected to grow as the older population increases and this dual need fits better with community embedded services.

The impact of LTCs on relationships is reported in the literature (Charmaz, 1997). The respite function is therefore the main requirement of some carers. However for those who want to spend time together, the centre can facilitate support that the relationship may need in order to undertake activities. This would not be possible for the couple, with pressure on the carer if attempting such activities without the support of the day care staff or volunteers.

## **10.8 Strengths and limitations**

### **10.8.1 Strengths**

This study is the first to combine an in depth understanding of day care services with client outcomes. It is unique in evaluating the support provided for older people with multiple long term conditions. It should be once again stressed that the services engaged in the project were not research active. Services were experiencing changes to funding streams, reduced budgets, alterations to referral systems and for some relocations and reorganisations. However, the methodology selected provided an inclusive non-threatening approach that maintained engagement with services despite these challenges. Observations enabled research barriers to be broken down and a greater understanding of service functioning was obtained to better inform research and practice.

As discussed in chapter 4, the concept of new client in day care services is different to a patient referred for treatment. Prior to commencing with a day service, whether referred by social services or another method, clients will often visit a small number of services. Firstly, day care providers are sensitive to the circumstances of the client and may wait a few weeks before deciding that the research study is suitable. This study provides an insight for future recruitment strategies for clients attending UK day care settings.

### **10.8.2 Limitations**

The study is an exploratory study. Clients were not randomised into services and numbers and gender or age were not controlled for in recruitment. The aim of the study is to open up discussion around the findings. The outcomes evident therefore cannot be solely attributed to the service type but could initiate discussion around the impact and effect of the service types.

Day centre managers provided clients with the project information sheet with the researcher's contact details. Initially, acting as gatekeepers the managers were selective in the types of clients that were given the information sheets. Services seemed to want to include clients who they felt would stay at the service and demonstrate positive experiences. This was addressed service by service in the early phase of the project to ensure services understood that the aim of the study was to better understand the service and this included its challenges. The flow of new clients did increase. The data presented in terms of outcomes and interviews is from those clients who were still attending at 12 weeks. The study did not follow clients who left the study. Therefore reasons for leaving the services and more negative experiences may not have been captured.

A key aim of the study was to explore services from both an urban and rural perspective. However the number of service users recruited from rural areas was lower than anticipated. This was due to the changing dynamic associated with provision to support access from rural areas discussed in chapters six and eight. In addition to one centre which recruited only rural participants, a further six centres were expected to recruit roughly one third of its clients from rural areas. During the course of the study, changes affecting transport from rural areas in these centres resulted in the sample in these centres only attending from urban areas.

The study obtained a baseline from clients within the first four weeks of attendance, the effects of the intervention may already have been in place. Therefore the baseline data may have been of a higher level than if obtained prior to clients starting with day care. To rectify this future studies could be closely aligned with the referral process in Paid services. However as referrals in Blended and Voluntary services are on an ad hoc basis this would not be possible in all service types. The most sensible solution would be for services to adopt the collection of baseline data for all new clients, adding to the knowledge base.

Whilst the carer status was collected from the client at baseline it was in terms of whether a carer lived with the client. This was to ensure the burden of measures was kept to a minimum. However a number of clients had a Paid carer and information was not obtained regarding carers' relationships in terms of differentiating between a partner or child, if there were multiple carers and if the carers were working or not. This would have provided supplementary information about the client group. However the focus of the study was to

understand the needs from the clients' perspective rather than the carers' that is more common when considering the respite model. The study therefore achieved this aim.

Social isolation is discussed within the thesis from data obtained from interviews. In quantitative terms loneliness is measured but not social isolation. Social isolation can be measured using the number of contacts within a given week and would be useful supporting data for a similar study to explore its relationship to emotional loneliness and social loneliness. There were indications from observations and interviews that clients' self-worth improved but this was not measured as part of the project so wider inference across the services could not be made.

### **10.9 Contribution to the literature**

This thesis extends the understanding of day care services from the perspective of clients with multiple LTCs. The systematic review presented in chapter three confirmed the paucity of research examining outcomes for attendees at day care and the absences of multiple LTCs in the literature. Studies in rural settings were also absent from the literature.

Where other studies including older people may focus on the carer's perspective, this study placed the client attending day care at the centre of the research study. Research pertaining to day care services often focuses on respite models for this reason. However, evidence revealed that the cumulative nature of loss through increasing number of LTCs led to client's seeking support from day care services rather than an episode of acute illness.

Whilst outsourcing is a growing phenomenon in supportive services and third sector and Voluntary organisations acknowledge their role in contributing to wider health determinants, little attention is paid to their role in the research literature. This thesis provides an understanding of this environment whilst also reporting outcomes by service type and geographical area. This thesis has embraced the complexity of the day care environment by an in depth exploration of various settings rather than merely providing supporting commentary as to the diversity of services. By utilising mixed methodology, the impact of service delivery could be assessed from the client's perspective with supporting information from carers, staff or volunteers. Reduced budgets and growing older populations on the horizon mean that configurations such as those observed will play an ever more important role in supporting people with LTCs. The results provide a strong baseline for further studies in this field.

#### **10.10 Contribution to Health Inequalities**

Health inequalities underpin the design ethos of this study as discussed in earlier chapters. Socially disadvantaged elderly people perceive greater barriers to accessing healthcare services than those who are better off (Hoebel et al 2017). This section will discuss the findings in relation to health inequalities in particular from the perspective of access to service type.

Clients attending paid staff services had to meet a needs threshold in order to access the service, whereby those attending blended and voluntary services did not. Therefore, it was expected that the number of long term conditions would differ across services. However, baseline data revealed that the number of long term conditions were comparable across all service types. When



comparing urban and rural areas, the number of long term conditions reported in rural areas was higher than in urban areas, reaching statistical significance.

On closer inspection the types of long term conditions revealed an interesting pattern suggesting the role that diagnosis may play in the access of different services. In all service types the most reported LTC was arthritis. However, when comparing the most commonly reported LTCs at paid staff services and voluntary services, the former included dementia, stroke and mental health conditions whereby heart disease and gastric conditions were more common at voluntary services. This suggests that personal care issues leading from a diagnosis of stroke and dementia may enable clients to meet the needs threshold in order to access day care services. Observations suggested that the needs threshold assessment may have facilitated access to other support in terms of equipment and devices that supported LTC needs, not as commonly observed in other services. Quantitative data collected using baseline EQ5D3L pain domain revealed that the reported levels of pain, although not reaching statistical significance at blended and voluntary services were higher than at paid staff services. It could be suggested that in addition to accessing equipment and devices, those at paid staff services were able to access to their services in order that pain may be manageable.

An additional benefit for those clients attending paid staff services was the additional support provided by services due to the information gleaned following a needs threshold assessment. Services were aware of their client's needs whereby blended services and voluntary services had to informally assess clients upon arrival at the centre. Clients accessing paid staff services

also had access to the accessible transport to travel to the centre whereas those attending blended and voluntary services were more likely to rely on family members, taxis, car share schemes or community transport. The latter if available was not dedicated solely to the blended or voluntary day centre, therefore there was no specialised knowledge of the client's needs or available escort to support people before, during or after the journey. In view of the frequency of bouts of illness of people with long term conditions, this presented challenges in blended and voluntary services created barriers for those who may want to attend during periods of poor health.

The inverse care law (Tudor-Hart, 1971) suggests that services are not provided in areas of greatest need however findings from this thesis did not suggest this was the case for day care service engaged with this study. A statistically significant higher proportion of those attending paid staff services lived in the most deprived LSOAs in England or Wales when compared with other service types. Therefore, this does suggest that local authority paid staff services are appropriately targeted to those communities.

The ethnicity of the sample was 100% white and whilst the rates of ethnicity were in the surrounding areas of blended and voluntary services were lower than the national average, the rates of ethnicity for areas where paid staff services were located were close to the national average and therefore raised additional questions around service provision for clients from ethnic minorities.

### **10.11 Implications for Practice**

This thesis has demonstrated that favourable outcomes can be achieved at services that are delivered or supported by volunteers. It suggested that the

reduction in emotional loneliness may be associated with the difference in how activities are delivered within Blended, Voluntary and rural services. Therefore the implication for practice is to deliver activities that promote self-worth, self-esteem and connections to the community.

Lessons can also be learnt from Paid staff services in terms of the management of LTCs. Accessibility of transport, sensory aids and supportive aids and devices were more common at Paid staff services enabling clients to remain engaged following loss of function due to illness. It is suggested that the training of Paid staff and a dedicated transport system contributed to the attendance of clients throughout periods of poor health when symptoms of their conditions were exacerbated. Referral systems for clients accessing Paid staff services ensured that staff were fully aware of clients' needs when they attended day care. In Blended and Voluntary service the lack of needs assessment resulted in services unaware if the clients' needs were appropriate for the service until attendance commenced.

The reduction in loneliness scores suggests an association with community engagement, so greater attention could be Paid in practice to the level of integration and community engagement the service provides. Services often share accommodation or space, but more attention could be Paid to enable greater interaction and engagement between groups sharing the facility so that integration is a practical rather than theoretical concept for services.

The statistical analysis of the EQ5D3L domains revealed that those with a higher number of LTCs were more likely to experience a reduction in reported problems over 12 weeks of attendance. However, those with a lower number of reported problems were more likely to experience an increase in reported

problems over 12 weeks of attendance. This suggests that services may be more beneficial to those with more LTCs. Those with a lower number of long terms conditions may still be adjusting to loss or diagnosis for which support would be beneficial.

### **10.12 Implications for Policy Makers**

The thesis has demonstrated that from a multiple LTCs perspective, day care services provided by volunteers support people with a similar number of LTCs as Paid staff services. Those attending rural services have a statistically significant higher number of LTCs than those attending services in urban areas. Therefore, non-traditional health organisations should be engaged with research into LTCs rather than those solely from a clinical health perspective.

This research study has demonstrated favourable outcomes in Blended and Voluntary services. In the current climate Paid staff services are increasingly moving towards a model whereby only those with a higher level of need are supported. The evidence provided in this thesis illustrates approaches for services that can contribute positively towards those use day care supported by volunteers. The prevalence of multiple LTCs is expected to increase with the growing numbers of older people. Understanding and designing services that provide positive outcomes are imperative in order that Blended and Voluntary services are sustainable in this context.

Whilst services are outsourced to Charitable and Voluntary organisations commissioner requirements remain diverse. To improve practice an understanding of outcomes at day care providers a baseline assessment could be implemented for new clients starting day care. This thesis has demonstrated the value that better understanding of client demographics and

support needs brings to the service. The methodology chosen here would be beneficial for organisations categorised as non- health. Methods embraced the complexity of the setting and provide findings relevant for the service increasing the likelihood of implementation.

The understanding of day care service configurations not only gives context required in a service renowned for its complexity and diversity of provision, it reveals the added value it brings for older people living in the community. Rather than viewing the service from a narrow viewpoint such as nutrition or falls prevention, examining the service as a whole demonstrated wider functions of day care such as monitoring fluid intake; medication prompts; safeguarding and liaising with clinical services. Therefore as social care moves more towards those in crisis or with higher level of need, policy makers may wish to utilise the role of day care as a more cost effective model for monitoring or prompting older people with support needs throughout the day.

In view of the findings relating to the transport requirements of day care clients, this is one area that action from policy makers is clearly necessary. It appears that community transport providers whilst focusing on the resourcing and operational issues of the service have lost a focus on the needs of clients along the way. As the level of LTCs is similar across all service types, the benefits of community transport dedicated to the centre was observed. It did not just provide access to the centre but enable more informed management and monitoring of people using the service, whether this was a centre owned bus or a community bus dedicated to the day care clients.

Other community transport was not flexible enough for clients' needs and the lack of rural clients at a number of services illustrated access issues in

particular areas. Clients not on dedicated transport would arrive later for sessions or leave early therefore not gaining the full benefit of attendance. Whilst services came up with innovative ways to negate community transport issues, this was reliant on particular staff or volunteer approaches. This did not present as a sustainable solution and there was awareness from day care that they were dependent on transport support to ensure access for clients was a viable option.

The choice of people with early stage dementia to attend generic day care services as opposed to specialised services should be considered by policy makers. Whilst there has been wider dementia awareness in society to ignore support given to early stage dementia patients in non-specialised services fails this overarching strategy. A holistic approach to the issue and dementia training at generic day care services would benefit this client group.

### **10.13 Areas for further research**

This section proposes as a result of the findings, that there are six broad themes of further research that would add value to this topic: Rural services; activities providing increased self-worth and esteem; training for volunteers and interlinking support services (transport); early stage dementia services; changing dyadic nature of carers and aging together; BME older people's needs for day care.

This thesis engaged with services across three service types and two geographical areas: Paid; Blended; Voluntary; Urban and Rural. However, the latter service presented difficulties due to the changing dynamic associated with provision to support access from rural areas. Further research, would be able to explore if the findings regarding lack of support services in rural areas

is unique to the day care environment or evident in other services. Research with a rural focus to regarding the services that support people in their own communities would be beneficial in this area.

It is suggested that the reason for a higher proportion of positive outcomes at Blended and Voluntary services may be due to the delivery of activities within the centres. Activities may facilitate a sense of purpose to the wider community and the enrichment of self. This may take the form of gaining new skills and knowledge or co-creating with other users. Research to explore this further would be beneficial to services supporting older people living in the community and care homes. Activities can also substitute previous interests no longer accomplishable due to sensory loss associated with LTCs. Further exploration of challenges and benefits of various activities in relation to disability experienced by older people with LTCs is needed.

The economic benefits of utilising services that require less resource to operate (Blended and Voluntary services) are clear for commissioning. However, adequate support and training of volunteers would benefit the service so that adequate support for a range of conditions could be given. Further research could investigate the training needs of services depending on volunteers. Advancing knowledge in this field would provide common criteria for Blended and Voluntary services rather than the complex differences presented to families requiring support. Research around the requirements of the interconnected services could reveal where more support is required.

Clients and carers with a diagnosis of dementia in the early stages reported that dementia specific services had not met their needs, due to the stage of

the condition. Research to determine how dementia specific services meet the needs of people within the early stages of the condition compared with generic day care services would provide a clearer understanding if this was a wider issue.

The day care literature refers to day care services as respite for families of older people. However the identity of the older person relying on support was brought into question by a small proportion of participants. In Blended and Voluntary services older people who were carers themselves attended the group, used it for time away from their caring role; other clients attended with their carers and there was evidence of carers with more than one older person to care for. The aging together and older people as carers theme, could be explored to understand the dynamic of clients that fall into this category. This emerging theme would enable the configuration of services to consider this growing population group within the aging demographic.

All participants recruited were of a white ethnic background. Further investigation into the needs of other ethnic groups with the aging demographic should be undertaken to explore the reasons behind the invisibility of clients from ethnic backgrounds in this project.

#### **10.14 Summary**

This section will describe the summary of findings from the thesis, initially discussing methodological findings then leading on to the findings from the empirical evidence.



The literature regarding day care is scarce with a lack of studies examining outcomes or the presence of LTCs. It is common for older people to be treated either as one homogenous group or from the perspective of a single disorder biomedical viewpoint. The challenge of research in the day care setting comes in two forms. Firstly to engage with a service under pressure with no experience of undertaking research and secondly to recruit from a population labelled as hard to reach and vulnerable due to their LTCs and frailty.

It is suggested that the early collaborative approach taken in the form of early visits to day care services and wider distribution of a survey, enabled the project designed to be relevant and topical for organisations involved. Rather than an anonymous survey distributed to the clients through day care services, the focused ethnography enabled a greater understanding of the context to be discovered. The approach broke down barriers, facilitated recruitment and follow up rates. It is suggested that the methodological approach be considered in future research of vulnerable groups.

During the design of the project a key aim was to ensure that tools and processes adopted were inclusive for the population group, due to the expected prevalence of sensory loss and disability. Measures selected were brief, consent processes included verbal consent for those with poor motor skills and formats were large so that clients with sight problems were not excluded. The carer's questionnaire was selected to provide a full understanding of various aspects of the carers' role. Two recommendations are made with regards to the consideration for the tools selected. Firstly it is suggested for future studies that the EQ5D5L be considered instead of the EQ5D3L. It was felt that although a number of client's at Paid staff services

relied on wheelchairs the baseline findings using the three point measure did not demonstrate this difference across client groups. It is suggested that the five point measure may provide further inference across services. However, it is not known if the self-reporting of problems may still have the same results due to the lack of acknowledgement by clients as to their level of physical loss.

It has been reported that people accessing Paid staff services had to pass a needs threshold level in order to access the service. The assessment provided to Paid staff services enabled the staff to appropriately manage the client needs and LTCs. Observations suggested that meeting the needs threshold may also enable the clients to access additional services such as mobility and communication aids and devices to support sensory loss were more common in Paid staff services.

Training and staff ratios at Paid staff services were complimentary to supporting clients with LTCs. The dedicated transport service at one Paid staff service provided greater range of activities based in the community and reassurance during periods of poor health. Despite the expected difference in the level of need between Paid staff services and other services baseline data revealed a similar number of LTCs. In rural areas client's had significantly higher number of conditions than in urban areas. Combining the findings at rural services, clients travelled significantly further in these areas compared with urban services, illustrating the barriers to accessing services in these areas in view of wider transport issues.

The types of LTCs reported varied by service and geographical area. It is suggested that access to Paid staff services may be due to the diagnosis of conditions such as stroke and dementia where issues with personal care may

be more prevalent. In rural areas there was a greater proportion of clients that reported cancer than in urban services.

Reviewing outcomes at six weeks follow up there was a significant difference by service type of reported problems of self care. The proportion of people attending Paid staff services and Blended services reported an increase in problems with self-care, with those attending Voluntary services reporting a reduction in problems. EQ5D3L problems reported at twelve weeks attendance demonstrated favourable outcomes for a service run by or supported by volunteers for all domains apart from usual activities. There was an association found between the number of LTCs clients reported and the increase in EQ5D3L problems at twelve weeks with those with fewer conditions more likely to report an increase in problems. It is suggested that day care providers may need to look at ways in which with client's still coming to terms with loss or disability be supported more effectively.

Loneliness outcomes at twelve weeks revealed that all services reported an overall reduction in loneliness scores. However, although all services saw a reduction in social loneliness, emotional loneliness did not reduce in Paid staff services, only in Blended or Voluntary services. When adjusted for other baseline variables in logistic regression modelling the likelihood of reduction in loneliness was increased in Blended and Voluntary services (OR=2.28 and OR=2.16 respectively).

Observations and interviews with clients, staff and volunteers suggested that activities were delivered with a different ethos across services. There was a greater lack of hierarchy between volunteers and clients than between Paid staff and clients. The activities provided in Blended and Voluntary groups

promoted group cohesion, connections, interactions, co-production, creativity and wider community engagement. Therefore it is suggested that this may account for the reductions in emotional loneliness demonstrated in Blended and Voluntary services.

In addition to the quantitative findings, emerging themes were also obtained from qualitative data. For example, there were issues for people with early stage dementia not wanting to access specialised services and instead opting to attend generic day care services. Observations revealed a wider role of day care services in terms of monitoring and safeguarding. There is evidence that a consequence of an aging population, is that people aging together with their partners is increasing. Couples accessed day care together in all Blended and Voluntary services. Additionally this project observed the dual role of older people as requiring support at day care but also using the service as respite from their caring role for partners or adult children with LTCs. Carers with more than one person to care for was a common occurrence and resulted in attrition in some services, with older people being placed in long term care. The relationship between carers and services was on an ad hoc basis and there was no evidence of any structured programmes of support for carers.

Older people with support needs are labelled as hard to reach and there are concerns from an ethical point of view that research may be inappropriate or intrusive. This project demonstrated that with the right approach and consideration of methods and tools, the population group are happy to take part in research studies.

### **10.15. Conclusion**

This thesis has provided positive evidence that day care improves health, wellbeing and independence and reduces loneliness levels in older people with LTCs. In addition to the outcomes assessed using quantitative methods the impact of day care is wider reaching than the features referred to above. The respite care model discussed in the literature often omits the experience of the day care client whilst involving the carer. This thesis places the client at the centre of the study and utilised flexible methods to ensure all aspects of day care could be explored.

Methodologically, this thesis promotes non-threatening and non-intrusive flexible methods that facilitate positive recruitment and follow up rates. It highlights that research in this environment, with this population group is possible, achievable and needed.

In addition to the favourable outcomes reported, this thesis provides a greater understanding of the type of people using particular service types and in geographical areas. The findings are useful for both commissioners and providers. It also highlights planning for policy makers in two key areas: accommodating people with early stage dementia in generic day care services and the changing role of older people's carers. As local authorities respond to reduced budgets by providing or funding diagnosis specific services, it was established that generic services are responsive to the needs of clients in the early stages of dementia. Whilst the respite model may be sought after by families, services that include volunteers offer flexibility for those clients and their carers who want to utilise services together. Such providers

accommodate the needs of the client and carer by enabling them to experience activities together.

Findings suggest that services may have a role to play in supporting people as their long term conditions develop. Those with fewer long term conditions were less likely to experience favourable outcomes relating to health. Services may focus further in this area in order to support clients in the earlier stages of developing long term conditions.

Day care services offer the opportunity for those unable to engage in society without support, to be introduced to activities in a non-threatening way. It is suggested that the biomedical model of health should not dominate activities. Activities that promote movement and cognitive function are valued by clients however, qualitative findings revealed the need to connect was a primary outcome valued at the centres.

The findings in this thesis are relevant for providers working with older people living in the community beyond the day care settings. This study opens up the debate as to how services in rural areas and with volunteers can be supported and developed to provide a sustainable service for older people with LTCs.

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## **Appendices:**

## Appendix 1: Quality Assessment Criteria for Systematic Literature Review

<p><b>1. Abstract and title: Did they provide a clear description of the study?</b></p> <p><b>Good:</b> Structured abstract with full information and clear title.  <b>Fair:</b> Abstract with most of the information.  <b>Poor:</b> Inadequate abstract.  <b>Very Poor:</b> No abstract.</p>
<p><b>2. Introduction and aims: Was there a good background and clear statement of the aims of the research?</b></p> <p><b>Good:</b> Full but concise background to discussion/study containing up-to date literature review and highlighting gaps in knowledge.  Clear statement of aim AND objectives including research questions.  <b>Fair:</b> Some background and literature review. Research questions outlined.  <b>Poor:</b> Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background.  <b>Very Poor:</b> No mention of aims/objectives. No background or literature review.</p>
<p><b>3. Method and data: Is the method appropriate and clearly explained?</b></p> <p><b>Good:</b> Method is appropriate and described clearly (e.g., questionnaires included).  Clear details of the data collection and recording.  <b>Fair:</b> Method appropriate, description could be better.  Data described.  <b>Poor:</b> Questionable whether method is appropriate.  Method described inadequately.  Little description of data.  <b>Very Poor:</b> No mention of method, AND/OR Method inappropriate, AND/OR No details of data.</p>
<p><b>4. Sampling: Was the sampling strategy appropriate to address the aims?</b></p> <p><b>Good:</b> Details (age/gender/race/context) of who was studied and how they were recruited.  Why this group was targeted.  The sample size was justified for the study.  Response rates shown and explained.  <b>Fair:</b> Sample size justified.  Most information given, but some missing.  <b>Poor:</b> Sampling mentioned but few descriptive details.  <b>Very Poor:</b> No details of sample.</p>
<p><b>5. Data analysis: Was the description of the data analysis sufficiently rigorous?</b></p> <p><b>Good:</b> Clear description of how analysis was done.  Qualitative studies: Description of how themes derived/ respondent validation or triangulation.  Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up/statistical significance discussed.  <b>Fair:</b> Descriptive discussion of analysis.  <b>Poor:</b> Minimal details about analysis.  <b>Very Poor:</b> No discussion of analysis.</p>
<p><b>6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?</b></p> <p><b>Good Ethics:</b> Where necessary issues of confidentiality, sensitivity, and consent were addressed.  <b>Good Bias:</b> Researcher was reflexive and/or aware of own bias.  <b>Fair:</b> These issues were acknowledged.  <b>Poor:</b> Brief mention of issues.  <b>Very Poor:</b> No mention of issues.</p>
<p><b>7. Results: Is there a clear statement of the findings?</b></p> <p><b>Good:</b> Findings explicit, easy to understand, and in logical progression.  Tables, if present, are explained in text.  Results relate directly to aims.  Sufficient data are presented to support findings.  <b>Fair:</b> Findings mentioned but more explanation could be given.  Data presented relate directly to results.  <b>Poor:</b> Findings presented haphazardly, not explained, and do not progress logically from results.  <b>Very Poor:</b> Findings not mentioned or do not relate to aims.</p>
<p><b>8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?</b></p> <p><b>Good:</b> Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).  <b>Fair:</b> Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.</p>



<p><b>Poor:</b> Minimal description of context/setting.</p> <p><b>Very Poor:</b> No description of context/setting.</p>
<p><b>9. Implications and usefulness: How important are these findings to policy and practice?</b></p> <p><b>Good:</b> Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.</p> <p><b>Fair:</b> Two of the above (state what</p> <p><b>Poor:</b> Only one of the above.</p> <p><b>Very Poor:</b> None of the above.</p>

## Appendix 2: Day Care for Older People Questionnaire



### Day Care for Older People Questionnaire

We are currently undertaking a research project about the types of day care provision available for older people. It would be appreciated if you could take the time to complete the questions below. The questionnaire is expected to take approximately 5-10 minutes to complete. It would be appreciated if you could return the completed questionnaire in the envelope provided. Thankyou.

#### 1. Contact Details

What is the name of your Day Centre	<input type="text"/>
Your Name	<input type="text"/>
Address	<input type="text"/>
Post Code	<input type="text"/>
Email	<input type="text"/>
Telephone	<input type="text"/>

#### 2. How is your provision funded? (please circle all that apply).

Local Authority

Voluntary

Private

Other

#### 3. How many places are there at your provision per day?

\_\_\_\_\_

#### 4. What is the cost of attending your day care per day?

\_\_\_\_\_

5. Does the cost above include transport? Yes / No

6. Does your day care provision arrange transport? Yes / No

#### 7. What is the cost, if any, charged to the local authority per person per session?

\_\_\_\_\_

#### 8. Please indicate the times your day care is open below

Monday	(eg, 10am – 4pm)	<input type="text"/>
Tuesday		<input type="text"/>

Wednesday

Thursday

Friday

Sat

Sun


9. Please indicate the activities or services provided at your day care provision eg, chair based exercises, craft, physio, O.T

Monday

Tuesday

Wednesday

Thursday

Friday

Sat

Sun


10. What are the care needs of people attending your provision?

Mild

Moderate

Severe

11. Does your service have any other specific inclusion criteria to attend your service? Eg age, dementia only?

12. Does your service have any additional specific exclusion criteria eg, mental health

13. How can people access your provision (please tick all that apply)

Self Referral

Local Authority Assessment

Referral from other agencies

14. How many Paid staff do you have at your centre per day?

\_\_\_\_\_

15. How many volunteers do you have at your centre per day?

\_\_\_\_\_

16. Please add any additional comments you would like us to know about your provision?

\_\_\_\_\_

17. We are currently researching how day care supports older people – would your service be interesting in knowing more about this research? Yes / No

Cath Lunt, NWC CLAHRC PhD Student, Health Services Research, University of Liverpool, Institute of Psychology, Health and Society, Waterhouse Building, Block B, 1<sup>st</sup> Floor, 1-5 Brownlow Street, Liverpool, L69 3GL contact: [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk) or 0151 794 5260 or 07788324427

## Appendix 3: Ethical Approval

Dear Prof Lloyd-Williams and Mrs Lunt,

I am pleased to inform you that your study has been approved. Details and conditions of the approval can be found below.

Ethics reference number: RETH000947

Committee name: Research Ethics Subcommittee for Non-Invasive Procedures

Review type: Full committee review

Title of study: Does day care promote wellbeing and independence and reduce social isolation for older people with moderate care needs and their carers? A rural and urban comparison

Principal Investigator: Professor Mari Lloyd-Williams

Student Investigator: Mrs Catherine Lunt

School/Institute: Institute of Psychology, Health and Society

First reviewer: Dr Jo Harrold

Approval date: 04/12/15

The application was APPROVED subject to the following conditions:

### Conditions

All serious adverse events must be reported to the Subcommittee within 24 hours of their occurrence, via the Research Integrity and Governance Officer ([ethics@liv.ac.uk](mailto:ethics@liv.ac.uk)).

This approval applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Subcommittee should be notified. If it is proposed to make an amendment to the research, you should notify the Committee by following the Notice of Amendment procedure. If the named PI / Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore please contact the Research Integrity and Governance Officer at [ethics@liverpool.ac.uk](mailto:ethics@liverpool.ac.uk) in order to notify them of a change in PI / Supervisor.

Kind regards,

Mantalena

---

Mantalena Sotiriadou  
Research Ethics and Integrity Officer

### Research Support Office

University of Liverpool  
Waterhouse Building (2nd Floor, Block C)  
3 Brownlow Street  
Liverpool  
L69 3GL  
Email: [M.Sotiriadou@liverpool.ac.uk](mailto:M.Sotiriadou@liverpool.ac.uk)  
Telephone: 0151 795 8355

# **NIHR CLAHRC North West Coast Health Inequalities Assessment Toolkit [HIAT]**

**The NIHR Collaboration for Applied Research and Care for the North West Coast (NIHR CLAHRC NWC) has developed this Health Inequalities Assessment Toolkit (HIAT) to help ensure that all our activities have potential to contribute to reducing health inequalities.**

**This document explains why we are focusing on the reduction of health inequalities and provides guidance on the use of the HIAT. There are also links to resources that may help those using HIAT to assess whether the work they wish to undertake is as sensitive as it can be to health inequalities and that it maximizes the impact it can have on reducing these. The HIAT website (<http://www.hiat.org.uk>) will be live shortly and will email you and alert.**

**CLAHRC NWC staff and partners developed the HIAT in a series of workshops in 2014-2015. This version of the HIAT is being piloted until 31<sup>st</sup> May and we welcome feedback on your experience of using it. This will enable us to refine the tool and related materials. You can find the feedback form in Appendix 2 at the end of the document**

**Version 1 for Pilot 27<sup>th</sup> March 2015**

**Contact: Ana Porroche-Escudero**

**Email: [a.porroche-escudero@lancaster.ac.uk](mailto:a.porroche-escudero@lancaster.ac.uk)**

**Project Title: The impact of day care services on older people  
with long term conditions**

**Section 1 – Clarifying the health inequality dimensions of the problem to be addressed in the proposed work**

Access to social care and day care services in the UK is both needs and means tested, creating disparity in access to and provision of day care services between socioeconomic groups (Age Concern, 2010). The system is such that people with similar need but with different income levels access services differently, with individuals supported by social care paying reduced rates.

In recent years local authorities supporting people with moderate care needs has reduced to less than 13% from 50%, (Age UK, 2014) and with further cuts expected to statutory budgets, it is believed older people with moderate needs and the services they access are at risk. In the absence of local authority services, new services are developing in the private, charitable and voluntary sector. The term inverse care law Tudor-Hart (1971) refers to the mismatch between need and supply whereby those living in deprived areas had more health problems but had shorter clinical encounters. Access to services in such areas takes longer with satisfaction with access significantly lower in deprived areas (Mercer et al 2007). In relation to day care people who live in deprived areas are likely to participate socially less than those who live in more affluent areas (Ferragina et al, 2013).

In rural areas where the proportion of older people is increasing at a faster rate than in urban areas it is suggested that health and social care models do not meet the needs of the aging population. This is due to the lack of younger families in rural areas, resulting in volunteer shortages and lack of local care staff (DEFRA, 2013). The service provided by volunteers in these areas is of particular value to people who rely heavily on services such as people with multiple LTCs (Gray and Leyland, 2013).

Visits took place to meet with day care service providers locally to discuss the current issues regarding day care. Some local authority services were in the process of outsourcing services for moderate needs and providing specialised dementia services. Meetings with staff and volunteers highlighted the role the recent Care Act legislation had impacted on their service plus changes to referrals and budgets received. The researcher was invited to take part in activities during which service users also talked

about issues that they found important. Majority of services did not specialise in one particular diagnosis but multiple diagnosis.

Key Points:

- Recent legislation impacted on criteria to access to services in terms of the moderate and substantial care need.
- Changes to referral process – as local authority rationalise services to look at substantial needs, moderate needs now referred by family.
- Access to services affected by configuration and links with other services, some people reliant on family to access services.
- Accessing services from rural areas, what are the issues? Urban centres currently encountering some issues with people waiting for transport to attend centre from rural areas due to scarcity of services.

The research study explores the models and their impact currently available for people accessing day care services focussing on those older people still living at home with moderate/ substantial care needs, with multiple long term conditions. Is there a difference in outcomes for people attending certain service provision?

## **Section 2 – Designing your intervention / action to maximize potential to reduce health inequalities**

Observations required to gather evidence and understand what the service is and how it supports people with long term conditions. Demographic information to be collected to understand the types of people using day care services and examine if there a difference in demographic using particular services. Include referral/ access issues in interviews and observations. Compare urban and rural services. Look at role of carers. Look at staff and volunteers, explore types of services, local authority, independent/private, charity and voluntary services.

Characteristics important to capture

- Gender
- Ethnicity
- Age
- Living arrangements
- Level of Deprivation
- Marital Status
- Carer Y/N
- Diagnosis / LTC
- Education

## **Section 3 – Evaluating and/or monitoring the impact of your activity on socio-economic inequalities in health**

Findings will be provided to services so that any inequalities in demographics highlighted can be addressed. Findings will also be available to commissioners of

services highlighting inequalities in provision or differences in outcomes. Barriers to access for some or priority of access for others will be examined.

Unintended outcomes for the project can also be captured due to the flexible nature of the methods used.

#### **Section 4 – Planning for wider impacts on health inequalities**

The findings will provide an understanding of inequalities as they impact on day care to inform commissioners and policy makers. This is expected to benefit not only day care services but other organisation providing services in the community to this population group. The methods utilised may benefit those working with hard to reach groups within the areas of research. Feedback to services engaged with the study will be provided at the end of the study. Services and users who wish to receive a summary of the findings will also be contacted at the end of the study. Dissemination will include written and oral publications within academic and community domains.



## **Appendix 5: Project Information Sheet for Day Care Managers**

### **Project Information Sheet**

#### **Impact of Day Care on Older People and their Carers**

##### **What is this study about?**

This study is examining the impact that day care provision has on older people who have moderate to substantial care needs and their carers. It hopes to capture the affect that attending day care has on people's physical, psychological and social wellbeing. It compares day care provided in urban and rural areas, exploring the various models of care provided by the statutory, independent, Charitable and Voluntary sectors.

##### **Why is this study being undertaken?**

There is a lack of research looking at the impact of day care on people with long term conditions. For people living with chronic or long term conditions, opportunities to engage with the wider community are limited. Recently, the impact of health and social care cuts and reorganisations have seen the landscape of day care provision changing. This study aims to look at examples of how day care is currently provided and what affect it has on promoting wellbeing and independence and reducing social isolation.

##### **How will this be done?**

Cath Lunt, a PhD research student from the University of Liverpool will spend time at the day care centre using a mixture of methods to gather data pertaining to the setting. She will attend the day centre for a few days and observe how the centre works and capture its uniqueness.

Participants who are new to the day care setting and their carers, will be asked to complete questionnaires regarding their wellbeing. This can take place during day care centres sessions or at another time and place convenient to the participant. There will be a visit shortly after the participant starts attending day care with questionnaires repeated 6 weeks and 12 weeks later and sent back in the post (envelope provided) or undertaken over the phone. The first visit is expected to take no longer than 30 minutes.

There is also an additional aspect of the study that a smaller number of participants will be asked to participate in, involving an interview to discuss their experiences of attending day care in more detail. Interviews will also be held with some staff or volunteers working in the day care settings.

##### **What would the day care provider need to do?**

The day care provider would be asked to agree to allow the researcher to observe activities in the centre. The day care manager would be asked to introduce the study to prospective participants who have recently started at the day care centre. If the participant expresses an interest in taking part in the research and agree to their details being passed to the researcher for this study, Cath will then contact them to provide more information about the

project. If they are still interested at this point the researcher will arrange a visit to enrol them into the study

**How will this study benefit the organisation and participants?**

There are no direct benefits from taking part in the study. Providers will be given a one page evaluation summarising the results of the research undertaken at their centre. The study will help us to find out more about the impact of day care on older people with moderate care needs and their carers.

**What if there is a problem or a complaint?**

If a problem arises please contact Cath Lunt on 07788 324 427 and we will try to help resolve the problem. If you remain unhappy please contact the University Research Governance officer on 0151 794 8290. When contacting the Research Governance Officer please tell them the name of the investigators, what the study is called which is at the top of this page and the nature of your complaint

**How is the study funded?**

The study is funded through National Institute of Health Research, Collaboration and Leadership in Applied Health Research and Care, North West Coast (NIHR, CLAHRC, NWC). It is funded for three years until February 2018.

**Next Steps – Contact Details**

If you are interested in knowing more about this study or would like to take part, please contact Cath Lunt, Research Student on 07788 324 427 or email [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk)

***V. August 2015***

## **Appendix 6: Participant Information Sheet**

### **Participant Information Sheet (P)**

**Title of the Study:** Impact of Day Care on Older People and their Carers.

#### **Invitation:**

You are being invited to take part in a research study. Before you decide to participate, please take time to read the following information carefully and feel free to ask us if you would like more information. You may also wish to discuss this with your family or friends.

#### **What is the purpose of this study?**

We know very little at the moment about what impact attending day care has on older people and their carers. The purpose of this study is to find out more about this and how it affects people's quality of life. This will help to decide how best to provide these services in the future.

#### **Why have I been chosen to take part?**

You have been asked to take part because you are due or have recently started to attend a day care centre. We would like to hear about your experiences to help us understand what impact attending the day centre has on you and your carer if you have one.

#### **Do I have to take part?**

No you do not. It is up to you whether you decide to take part. It is entirely Voluntary and you can decide to withdraw from this study at any time without giving a reason.

#### **What will happen to me if I do take part?**

If you decide to take part, the researcher Cath Lunt, will contact you over the telephone and discuss the study with you in more detail. If you would still like to participate, she will then make an appointment to come and see you either at day care or at your home and record your consent.

At the first appointment, usually within the first 2 weeks of you attending day care, the researcher will ask you to complete a series of questionnaires which should take no more than 30 minutes in total. At the end of the first appointment will explain about repeating the tests at a later date (6 weeks and 12 weeks later) and will telephone you to remind you when to complete them. The questionnaires can be completed and returned in the post using an envelope provided or can be undertaken over the telephone if you would find this easier. If you have a carer the researcher will ask permission to contact them to discuss their participation in the study.

The study will ask some participants if they would like to take part in a more detailed discussion about attending the day care centre, so Cath may discuss this with you. If you would like to take part, Cath will record the interview (approx. 45 minutes), with your consent and permission. This will mean she can concentrate fully on what you are telling her without having to take notes.

#### **What are the benefits of taking part?**

There are no direct benefits to you in taking part in this study. If you decide to take part in this study, you will help us to find out more about the impact of day care on older people with moderate needs and their carers.

**Are there any disadvantages to taking part?**

It is not expected that there will be any disadvantages from taking part. There is a small possibility that you may feel upset when thinking about your answers to the questionnaires or when taking part in the more detailed interview. If you wish, the researcher will stop the recording and discontinue the interview. If you prefer, the interview can be arranged for another time or you may decide not to continue at all.

**What if I am unhappy or there is a problem?**

If you are unhappy at all please contact Cath Lunt on 07788 324427 and we will try to help resolve the problem. If you remain unhappy please contact the University Research Governance Officer on 0151 794 8290.

**Will the information I give be kept confidential?**

The data given in your questionnaires will be anonymised and kept confidential. They will be stored in a locked filing cabinet. The researcher will make sure that the tape and any transcript from your interview are anonymous and kept safe at the University in a lockable cabinet and University secure network.

**What will happen to the findings from this study?**

The findings will be published in international and national journals and may be presented at conferences and research meetings. This is so as many people as possible can hear about the findings and take action in the future. A summary of the findings will also be available to you if you wish. The findings will also form the basis of the researcher's PhD thesis for examination by the University of Liverpool.

**What will happen if I decide I do not want to continue taking part?**

If at any time you decide you do not want to carry on taking part in the study you will need to contact the researcher on 07788 324427 or [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk). Your participation is Voluntary and your withdrawal will have no consequences for you whatsoever.

**Who do I contact if I have further questions?**

If you have any more questions about this study, please contact Cath Lunt, 07788 324 427 [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk). Cath Lunt is a researcher working with the Principal Investigator, Professor Mari Lloyd-Williams at the University of Liverpool. This study is being funded by NIHR, CLAHRC, NWC(National Institute for Health Research, Collaboration and Leadership in Applied Health Research and Care, North West Coast) and has been reviewed by the University of Liverpool Research Ethics Committee.

**August 2015**

## **Appendix 5: Project Information Sheet Client**

### **Participant Information Sheet (P)**

**Title of the Study:** Impact of Day Care on Older People and their Carers.

**Invitation:**

You are being invited to take part in a research study. Before you decide to participate, please take time to read the following information carefully and feel free to ask us if you would like more information. You may also wish to discuss this with your family or friends.

**What is the purpose of this study?**

We know very little at the moment about what impact attending day care has on older people and their carers. The purpose of this study is to find out more about this and how it affects people's quality of life. This will help to decide how best to provide these services in the future.

**Why have I been chosen to take part?**

You have been asked to take part because you are due or have recently started to attend a day care centre. We would like to hear about your experiences to help us understand what impact attending the day centre has on you and your carer if you have one.

**Do I have to take part?**

No you do not. It is up to you whether you decide to take part. It is entirely voluntary and you can decide to withdraw from this study at any time without giving a reason.

**What will happen to me if I do take part?**

If you decide to take part, the researcher Cath Lunt, will contact you over the telephone and discuss the study with you in more detail. If you would still like to participate, she will then make an appointment to come and see you either at day care or at your home and record your consent.

At the first appointment, usually within the first 2 weeks of you attending day care, the researcher will ask you to complete a series of questionnaires which should take no more than 30 minutes in total. At the end of the first appointment will explain about repeating the tests at a later date (6 weeks and 12 weeks later) and will telephone you to remind you when to complete them. The questionnaires can be completed and returned in the post using an envelope provided or can be undertaken over the telephone if you would find this easier. If you have a carer the researcher will ask permission to contact them to discuss their participation in the study.

The study will ask some participants if they would like to take part in a more detailed discussion about attending the day care centre, so Cath may discuss this with you. If you would like to take part, Cath will record the interview (approx. 45 minutes), with your consent and permission. This will mean she can concentrate fully on what you are telling her without having to take notes.

**What are the benefits of taking part?**

There are no direct benefits to you in taking part in this study. If you decide to take part in this study, you will help us to find out more about the impact of day care on older people with moderate needs and their carers.

**Are there any disadvantages to taking part?**

It is not expected that there will be any disadvantages from taking part. There is a small possibility that you may feel upset when thinking about your answers to the questionnaires or when taking part in the more detailed interview. If you wish, the researcher will stop the recording and discontinue the interview. If you prefer, the interview can be arranged for another time or you may decide not to continue at all.

**What if I am unhappy or there is a problem?**

If you are unhappy at all please contact Cath Lunt on 07788 324427 and we will try to help resolve the problem. If you remain unhappy please contact the University Research Governance Officer on 0151 794 8290.

**Will the information I give be kept confidential?**

The data given in your questionnaires will be anonymised and kept confidential. They will be stored in a locked filing cabinet. The researcher will make sure that the tape and any transcript from your interview are anonymous and kept safe at the University in a lockable cabinet and University secure network.

**What will happen to the findings from this study?**

The findings will be published in international and national journals and may be presented at conferences and research meetings. This is so as many people as possible can hear about the findings and take action in the future. A summary of the findings will also be available to you if you wish. The findings will also form the basis of the researcher's PhD thesis for examination by the University of Liverpool.

**What will happen if I decide I do not want to continue taking part?**

If at any time you decide you do not want to carry on taking part in the study you will need to contact the researcher on 07788 324427 or [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk). Your participation is voluntary and your withdrawal will have no consequences for you whatsoever.

**Who do I contact if I have further questions?**

If you have any more questions about this study, please contact Cath Lunt, 07788 324 427 [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk). Cath Lunt is a researcher working with the Principal Investigator, Professor Mari Lloyd-Williams at the University of Liverpool. This study is being funded by NIHR, CLAHRC, NWC(National Institute for Health Research, Collaboration and Leadership in Applied Health Research and Care, North West Coast) and has been reviewed by the University of Liverpool Research Ethics Committee.

**August 2015**

## Appendix 7: Participant Consent Form

Committee on Research Ethics

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### PARTICIPANT CONSENT FORM

#### Quantitative Data

**Title of Research Project** - Impact of Day Care on Older People and their Carers

**Researcher** Cath Lunt  
**Initial**

#### Box

1. I confirm that I have read and have understood the information sheet dated August 2015 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is Voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected.  
  
In addition, should I not wish to answer any particular question or questions, I am free to decline.
3. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications.
4. I agree to take part in the above study.

☐☐☐☐

\_\_\_\_\_  
Participant Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Student Researcher:** Cath Lunt, IPHS, Waterhouse Building, Block B, 1<sup>st</sup> Floor, 1-5 Brownlow Street, Liverpool, L69 3GL. Email: [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk) Tel: 07788 324427

**Appendix 8: Contact Details form**

Participant ID
----------------

**Participant Contact Details Form****Name** \_\_\_\_\_**Address** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_**Telephone** \_\_\_\_\_  
\_\_\_\_\_**Carer Name** \_\_\_\_\_**Relationship** \_\_\_\_\_**Address** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_**Telephone** \_\_\_\_\_  
\_\_\_\_\_**Email** \_\_\_\_\_





## Appendix 9: Demographic Questionnaire

Participant ID

### Participant Details

A Please give your age \_\_\_\_\_

B Please indicate your gender

Male ☐ Female ☐

Prefer not to say ☐

C Please indicate your ethnicity (please tick one box).

☐ White – British

☐ White – Irish

☐ White – Any Other

☐ Mixed – White and Black Caribbean

☐ Mixed – White and Black African

☐ Mixed – White and Asian

☐ Mixed – Any other mixed background

☐ Asian / Asian British – Indian

☐ Asian/Asian British – Pakistani

☐ Asian/Asian British-Bangladeshi

☐ Asian/Asian British-Any other Asian

☐ Black / Black British – Caribbean

☐ Black/ Black British – African

☐ Black / Black British – Any other

☐ Chinese

☐ Any other ethnic background

☐

Prefer not to say

D What is your Current Marital Status? ( Please tick one box below)

☐ Currently Married

☐ Separated or Divorced

☐ Widowed

☐ Never Married

☐ Prefer not to say

E What is your postcode? \_\_\_\_\_

F Please indicate which statement best indicates your living arrangements?

☐ Partner is present – no children

☐ Children are present but no partner

☐ Person lives with other adults (relatives or otherwise)

☐ Partner and children are present

☐ I live alone

G Please indicate which statement best indicates your residential status?

- ☐ I rent my home from a local council
- ☐ I rent my home from a social housing landlord
- ☐ I rent my home privately
- ☐ I own my own home with no mortgage
- ☐ I own my home with a mortgage
- ☐ I do not own or rent my home, I live with a relative or friend in their home
- ☐ I do not own or rent my home, I live with a relative or friend in their annexe
- ☐ Other

H Please indicate if you have help that you do not pay for eg from a family member or friend?

- ☐ I have a carer who is a family member that lives with me
- ☐ I have a carer who is lives with me but is not a family member
- ☐ I have a carer who is a family member that does not live with me
- ☐ I have a carer who is not a family member and does not live with me
- ☐ I do not have a carer

I. Please indicate which statement best indicates the qualifications you achieved?

- ☐ I hold no educational or vocational qualifications
- ☐ I have educational or vocational qualifications but not a University degree
- ☐ I hold a University degree or above.



## Appendix 10: Long Term Conditions Questionnaire

Please indicate if you have any of the conditions listed below in each box and if you so wish give additional details on the accompanying line.

Yes	No	Long Term Condition	Additional Information
<input type="checkbox"/>	<input type="checkbox"/>	Stroke	_____
<input type="checkbox"/>	<input type="checkbox"/>	Arthritis	_____
<input type="checkbox"/>	<input type="checkbox"/>	Diabetes	_____
<input type="checkbox"/>	<input type="checkbox"/>	Respiratory Disease , eg Asthma, COPD	_____
<input type="checkbox"/>	<input type="checkbox"/>	Dementia / Alzheimers	_____
<input type="checkbox"/>	<input type="checkbox"/>	Neurological , eg <i>Parkinsons, Epilepsy</i>	_____
<input type="checkbox"/>	<input type="checkbox"/>	Cancer	_____
<input type="checkbox"/>	<input type="checkbox"/>	Renal eg, Kidney Disease	_____
<input type="checkbox"/>	<input type="checkbox"/>	Thyroid	_____
<input type="checkbox"/>	<input type="checkbox"/>	Osteoporosis	_____
<input type="checkbox"/>	<input type="checkbox"/>	Gastric <i>eg Reflux, Ulcer</i>	_____
<input type="checkbox"/>	<input type="checkbox"/>	Mental Health <i>eg Depression</i>	_____
<input type="checkbox"/>	<input type="checkbox"/>	Learning Disability	_____
<input type="checkbox"/>	<input type="checkbox"/>	Eyes eg Cataract	_____
<input type="checkbox"/>	<input type="checkbox"/>	Ears eg Hearing Loss	_____

**Other: If you have another Long Term Condition not listed above, please feel free to mention here**

## Appendix 11: Loneliness Scale

Participant ID



**Part A – Please read the following statements 1, 2 and 3 and circle the response below that most applies to you.**

1) I am content with my friendships and relationships

Strong Disagree / Disagree / Neutral / Agree / Strong Agree / Don't know

2) I have enough people I feel comfortable asking for help at any time

Strongly Agree / Agree / Neutral / Disagree / Strongly Disagree / Don't know

3) My relationships are as satisfying as I would want them to be

Strong Disagree / Disagree / Neutral / Agree / Strong Agree / Don't know

**Part B – Please read the following statement below and circle the response that you feel most applies to you**

I experience a general sense of emptiness

Yes / More or Less / No

I miss having people around me

Yes / More or Less / No

I often feel rejected

Yes / More or Less / No

There are plenty of people I can rely on when I have problems

Yes / More or Less / No

There are many people I can trust completely

Yes / More or Less / No

There are enough people I feel close to

Yes / More or Less / No

## **Appendix 12: EQ5D3L**

### **Health Questionnaire**

**English version for the UK**

***(Validated for Ireland)***

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

### **Mobility**

- I have no problems in walking about ☐
- I have some problems in walking about ☐
- I am confined to bed ☐

### **Self-Care**

- I have no problems with self-care ☐
- I have some problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

### **Usual Activities** (*e.g. work, study, housework, family or leisure activities*)

- I have no problems with performing my usual activities ☐
- I have some problems with performing my usual activities ☐
- I am unable to perform my usual activities ☐

### **Pain / Discomfort**

- I have no pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have extreme pain or discomfort ☐

### **Anxiety / Depression**

- I am not anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am extremely anxious or depressed ☐

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Your own health  
state today**

Best imaginable  
health state

100

90

80

70

60

50

40

30

20

10

0

Worst imaginable  
health state

**Appendix 13: 12 week client satisfaction survey**  
**12 Week Satisfaction Questionnaire**

If you would like the researcher to contact you about anything in the questionnaire please contact Cath Lunt on 07788324427

1. Please let us know how you feel about the following statement.

I feel my life since attending the day service is

Worse / Same / Better/ Much Better

2. Can you tell us more about your response above.

For example if you feel your life is generally better since attending day service, in what way? If your life is same or worse – can you please tell us in what way?

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---

---

3. What do you feel have been three best things about attending day care

---

---

---

---

4. What do you feel have been the three worst things about attending day care

---

---

---



## **Appendix 14: Participant Information Sheet (Carers)**



### **Participant Information Sheet (C) Carers**

**Title of the Study:** Impact of Day Care on Older People and their Carers.

#### **Invitation:**

You are being invited to take part in a research study. Before you decide to participate, please take time to read the following information carefully and feel free to ask us if you would like more information. You may also wish to discuss this with your family or friends.

#### **What is the purpose of this study?**

We know very little at the moment about what impact attending day care has on older people and their carers. The purpose of this study is to find out more about this and how it affects people's quality of life. This will help to decide how best to provide these services in the future.

#### **Why have I been chosen to take part?**

You have been asked to take part because the person you care for has recently started to attend a day care centre. We would like to hear about your experiences to help us understand what impact attending the day centre has on you and the person you care for.

#### **Do I have to take part?**

No you do not. It is up to you whether you decide to take part. It is entirely Voluntary and you can decide to withdraw from this study at any time without giving a reason.

#### **What will happen to me if I do take part?**

If you decide to take part, the researcher Cath Lunt, will contact you over the telephone and discuss the study with you in more detail. If you would still like to participate she will then make an appointment to come and see you either at day care or at your home and record your consent.

At the first appointment, usually within the first 2 weeks of the person you care for attending day care, the researcher will ask you to complete a questionnaire which should take no more than 10 minutes in total. The questionnaire will be repeated 6 and 12 weeks later. The researcher will contact you over the phone to remind you when to complete the questionnaire which can be returned in the post in an envelope provided or undertaken over the phone if that is easier for you.

The study will ask some participants if they would like to take part in a more detailed discussion about the person they care for attending the day care centre, so the researcher may discuss this with you. If you would like to take part, the researcher will record the interview (approx. 45 minutes), with your consent and permission. This will mean she can concentrate fully on what you are telling her without having to take notes.

#### **What are the benefits of taking part?**

There are no direct benefits to you in taking part in this study. If you decide to take part in this study you will help us to find out more about the impact of day care on older people with moderate needs and their carers.

**Are there any disadvantages to taking part?**

It is not expected that there will be any disadvantages from taking part. There is a small possibility that you may feel upset when thinking about your answers to the questionnaires or when taking part in the more detailed interview. If you wish, the researcher will stop the recording and discontinue the interview. If you prefer, the interview can be arranged for another time or you may decide not to continue at all.

**What if I am unhappy or there is a problem?**

If you are unhappy at all please Cath Lunt on 07788 324 427 and we will try to help resolve the problem. If you remain unhappy please contact the University Research Governance officer on 0151 794 8290.

**Will the information I give be kept confidential?**

The data given in your questionnaires will be anonymised and kept confidential. They will be stored in a locked filing cabinet. The researcher will make sure that the tape and any transcript from your interview are anonymous and kept safe at the University in a lockable cabinet and the University secure network.

**What will happen to the findings from this study?**

The findings will be published in international and national journals and may be presented at conferences and research meetings. This is so as many people as possible can hear about the findings and take action in the future. A summary of the findings will also be available to you if you wish. The findings will also form the basis of the researcher's PhD thesis for examination by the University of Liverpool.

**What will happen if I decide I do not want to continue taking part?**

If at any time you decide you do not want to carry on taking part in the study you will need to contact Cath Lunt, 07788 324 427. Your participation is Voluntary and your withdrawal will have no consequences for you whatsoever, although any data collected will be still included anonymously in the study up until the point of the withdrawal.

**Who do I contact if I have further questions?**

If you have any more questions about this study, please contact Cath Lunt, 07788 324 427 [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk). Cath Lunt is a researcher working with the Principal Investigator, Professor Mari Lloyd-Williams at the University of Liverpool. This study is being funded by NIHR, CLAHRC, NWC(National Institute for Health Research, Collaboration and Leadership in Applied Health Research and Care, North West Coast) and has been reviewed by the University of Liverpool Research Ethics Committee

***Version August 2015***

## Appendix 15: Carer Consent Form Quantitative Data

### Committee on Research Ethics

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#### PARTICIPANT CONSENT FORM (C) – CARER

#### QUANTITATIVE DATA

**Title of Research Project** - Impact of Day Care on Older People and their Carers

**Researcher** Cath Lunt

1. I confirm that I have read and have understood the information sheet dated August 2015 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is Voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline.

☐

3. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications.

☐

4. I agree to take part in the above study.

☐

Participant Name	Date	Signature
Name of Person taking consent	Date	Signature
Researcher	Date	Signature

**Student Researcher:** Cath Lunt, IPHS, Waterhouse Building, Block B, 1<sup>st</sup> Floor, 1-5 Brownlow Street, Liverpool, L69 3GL Email: [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk) Tel: 07788 324427

## Appendix 16: AcQoL The Adult Carer Quality of Life Questionnaire (AC-QoL)

### How to Fill in the Questionnaire

This questionnaire asks you about different aspects of your life as a carer. Please think about your experience as a carer within the last two weeks and please tick the box that applies next to each statement. There are no right or wrong answers; we are just interested in what life is like for you as a carer.

Please answer all questions as honestly as you can.

	Never	Some of the Time	A lot of the Time	Always
<b>Support for Caring</b>				
01. I have a good level of emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
02. My needs as a carer are considered by professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
03. I am happy with the professional support that is provided to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
04. I feel able to get the help and information I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
05. I have all the practical support I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Caring Choice</b>				
06. I feel that my life is on hold because of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
07. My social life has suffered because of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
08. I feel I have less choice about my future due to caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
09. I feel I have no control over my own life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Caring stops me doing what I want to do

Never	<input type="checkbox"/> Some of the time	<input type="checkbox"/> A lot the time	<input type="checkbox"/> Always
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**Caring Stress**

11. I feel depressed due to caring

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

12. I feel worn out as a result of caring

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

13. I am mentally exhausted by caring

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

14. I am physically exhausted by caring

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

15. I feel stressed as a result of caring

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

**Money Matters**

16. I worry about going into debt

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

17. I feel satisfied with my financial situation

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

18. I am able to save for a rainy day

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

19. I worry about money

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

20. There is enough money in our house to pay for the things we need

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

	Never	Some of the time	A lot the time	Always
<b>Personal Growth</b>				
21. I have become a more tolerant person through my caring role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Because of caring, I have learnt a lot about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Because of caring, I feel that I have grown as a person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I have experienced many positive things through caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I feel that I have become a better person by caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Sense of Value</b>				
26. I feel valued by the person I am looking after	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. The person I look after respects me for what I do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. The person I look after makes me feel good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				<input type="checkbox"/>

- |  |                          |                          |                          |                          |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| 29. I get a lot from the person I am looking after             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |                          |
| 30. I have a good relationship with the person I am caring for | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- |   | Never                    | Some of<br>the time      | A lot<br>the time        | Always                   |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| <b>Ability to Care</b>  |                          |                          |                          |                          |
| 31. I am satisfied with my performance as a carer                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 32. I can take care of the needs of the person I am caring for                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 33. I feel I am able to make the life of the person I am looking after better | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 34. I can manage most situations with the person I care for                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 35. I am able to deal with a difficult situation                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Carer Satisfaction</b>   |                          |                          |                          |                          |
| 36. Caring is important to me   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 37. I resent having to be a carer   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

38. I feel frustrated with the person I am caring for

☐☐☐☐

39. I enjoy being a carer

☐☐☐☐

40. I am satisfied with my life as a carer

☐☐☐☐

**A. Please give your age** \_\_\_\_\_

**B Please indicate your gender** (please tick)

Male

☐

Female

☐

Prefer not to say

☐

**C Please indicate your ethnicity** (please tick one box)

White - British

White - Irish

White - any other

Mixed - White and Black Caribbean

Mixed - White and Black African

Mixed - White and Asian

Mixed - Any other mixed background Chinese

Any other ethnic background

☐  
☐  
☐  
☐  
☐  
☐  
☐  
☐

Asian/Asian British – Pakistani

Asian/Asian British - Bangladeshi

Asian/Asian British - Any other Asian

Asian/Asian British - Indian

Black/Black British - Caribbean

Black/Black British - African

Black/Black British - Any other

☐  
☐  
☐  
☐  
☐  
☐  
☐  
☐

**D How many hours do you spend caring per week?** (please tick)



0-10 hours	<input type="checkbox"/>	11-20 hours	<input type="checkbox"/>	21-30 hours	<input type="checkbox"/>	31-40 hours	<input type="checkbox"/>
41-50 hours	<input type="checkbox"/>	51-60 hours	<input type="checkbox"/>	61-70 hours	<input type="checkbox"/>	Greater than 71-hours	<input type="checkbox"/>

**E How long have you been a carer for?** \_\_\_\_\_

**Appendix 17: Participant Consent Form Interview**  
**Committee on Research Ethics**

**PARTICIPANT CONSENT FORM**

**Interview**

**Title of Research Project:** Impact of Day Care on Older People and their Carers

**Researcher:** Cath Lunt

1. I confirm that I have read and have understood the information sheet dated August 2015 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is Voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline.

☐

3. I understand and agree that my participation will be audio recorded and I am aware of and I agree to this and the use of any information I give being used in anonymous form in publications, conference presentations or similar events.

☐

4. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications.

☐

5. I agree to take part in the above study.

☐

\_\_\_\_\_  
Participant Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Student Researcher:** Cath Lunt, IPHS, Waterhouse Building, lock B, 1<sup>st</sup> Floor,  
1-5 Brownlow Street, Liverpool, L69 3GL  
Email: [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk) Tel: 07788 324427

**Appendix 17: Consent Form Interview Carer**  
**Committee on Research Ethics**

**PARTICIPANT CONSENT FORM (C) – CARER**

**SEMI-STRUCTURED INTERVIEW**

**Title of Research Project** - Impact of Day Care on Older People and their Carers

**Researcher** Cath Lunt

1. I confirm that I have read and have understood the information sheet dated August 2015 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is Voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline.
3. I understand and agree that my participation will be audio recorded and I am aware of and I agree to this and the use of any information I give being used in anonymous form in publications, conference presentations or similar events.
4. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications.
5. I agree to take part in the above study.

_____ Participant Name	_____ Date	_____ Signature
_____ Name of Person taking consent	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

**Student Researcher:** Cath Lunt, IPHS, Waterhouse Building, Block B, 1<sup>st</sup> Floor, 1-5 Brownlow Street, Liverpool, L69 3GL

Email: [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk) Tel: 07788 324427

## **Appendix 18: Staff / volunteer Interview Information Sheet**

### **Participant Information Sheet (Staff / Volunteers)**

**Title of the Study:** Impact of Day Care on Older People – Feasibility Study.

#### **Invitation:**

This study is examining the impact that day care provision has on older people who have moderate to substantial care needs and their carers. It hopes to capture the affect that attending day care has on people's physical, psychological and social wellbeing and assess differences in accessing health care services, when compared with people who do not attend day care.

#### **What is the purpose of this study?**

We know very little at the moment about what effect day care has on older people and their carers. The purpose of this study is to find out more about this, how it affects people's quality of life, whether it alters other appointments you may have. This will help to decide how best to provide these services in the future.

#### **Why have I been chosen to take part?**

You have been asked to take part because you work or volunteer at a day care centre taking part in this study. We would like to hear about your experiences to help us understand the impact the day centre has on people using it.

#### **Do I have to take part?**

No you do not. It is up to you whether you decide to take part. It is entirely Voluntary and you can decide to withdraw from this study at any time without giving a reason.

#### **What will happen to me if I do take part?**

If you decide to take part, the researcher Cath Lunt, will discuss the study with you in more detail. If you would still like to participate she will then ask you to sign a consent form.

The researcher will record the interview (approx. 30-45 minutes), with your consent and permission. This will mean she can concentrate fully on what you are telling her without having to take notes.

#### **What are the benefits of taking part?**

There are no direct benefits to you in taking part in this study. If you decide to take part in this study you will help us to find out more about the impact of day care on older people with moderate needs and their carers.

#### **Are there any disadvantages to taking part?**

It is not expected that there will be any disadvantages from taking part.

#### **What if I am unhappy or there is a problem?**

If you are unhappy at all please Cath Lunt on 07788 324 427 and we will try to help resolve the problem. If you remain unhappy please contact the University Research Governance officer on 0151 794 8290.

**Will the information I give be kept confidential?**

The information you give will be anonymised and kept confidential. It will be stored in a locked filing cabinet. The researcher will make sure that the tape and any transcript from your interview are anonymous and kept safe at the University in a lockable cabinet and the University secure network.

**What will happen to the findings from this study?**

The findings will be published in international and national journals and may be presented at conferences and research meetings. This is so as many people as possible can hear about the findings and take action in the future. A summary of the findings will also be available to you if you wish.

**What will happen if I decide I do not want to continue taking part?**

If at any time you decide you do not want to carry on taking part in the study you will need to contact Cath Lunt , 07788 324 427. Your participation is Voluntary and your withdrawal will have no consequences for you whatsoever.

**Who do I contact if I have further questions?**

If you have any more questions about this study, please contact Cath Lunt, 07788 324 427 [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk). Cath Lunt is a researcher working with the Chief Investigator, Professor Mari Lloyd-Williams at the University of Liverpool. This study is being funded by NHS Liverpool Clinical Commissioning Group and has been reviewed by the NHS Research Ethics Committee

## Appendix 18: Staff/ Volunteer Interview Consent Form

### Committee on Research Ethics

### PARTICIPANT CONSENT FORM

#### Staff / Volunteers

**Title of Research Project** - Impact of Day Care on Older People and their Carers

**Researcher** Cath Lunt

1. I confirm that I have read and have understood the information sheet dated Aug 2015 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is Voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline.

☐

3. I understand and agree that my participation will be audio recorded and I am aware of and I agree to this and the use of any information I give being used in anonymous form in publications, conference presentations or similar events.

☐

4. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications.

☐

5. I agree to take part in the above study.

☐

\_\_\_\_\_  
Participant Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Student Researcher:** Cath Lunt, IPHS, Waterhouse Building, Block B, 1<sup>st</sup> Floor, 1-5 Brownlow Street, Liverpool, L69 3GL. Email: [c.a.lunt@liverpool.ac.uk](mailto:c.a.lunt@liverpool.ac.uk) Tel: 07788 324427

**Appendix 19: Distress Protocol**  
**Impact of Day Care for Older People and their Carers.**

**DISTRESS PROTOCOL**

In the event of a study participant becoming distressed the following courses of action will be taken:

- Distress exhibited by participants prior to the data collection/ interview will be sensitively addressed by the researcher. The cause of the distress will be established and discussed if participant wishes. The researcher, in collaboration with the participant, will establish whether to proceed with the interview, re-schedule or continue inclusion in the study.
- If participants demonstrate any signs of distress during the interview, the process will be suspended by the researcher, (tape switched off). Participants will be allowed to ventilate feelings/emotions if desired. Researcher and participant will collaboratively decide upon their ability to continue the interview following a “time out” period.
- If researcher and participant agree, interview will proceed.
- If the level of distress exhibited necessitates complete suspension of the interview, both will discuss the appropriateness of re-scheduling. If both agree the level of distress warrants withdrawal from the study, this will occur.
- If the interview is re-scheduled, the researcher will be aware of the potential for distress and act accordingly on the future visit.
- If distress occurs following the interview, researcher to sensitively address this in collaboration with participant.
- Researcher to establish if participant wishes any data obtained to be used in the final analysis. Wishes of participant will be respected.
- If the participant is distressed, with their permission, the day care manager will be informed, and participants will also be encouraged to talk about the cause of their distress with their health care professional eg community nurse or GP or social worker / paid carer as applicable For home visits the researcher will sit and listen and offer support. The participant will be asked if they wish the researcher to contact a family member or friend. If the participant gives permission, the researcher will let the centre manager know of distress.

## **Appendix 20: Topic Guide and Questions for Semi Structured Interviews with Participants and Carers**

### **Topic Guide**

- Circumstances that lead to accessing day care, illness, crisis, widowhood, isolation
- How did they access the service, recommended, support, referrals
- Has it helped? What's worked well, not so well? Wider issues with other services eg transport
- What would they do if they were unable to use this service?

### **Questions – Clients / Attendees at day care**

Could you start by telling me a little about why / what lead you to start using the day care service

Was there anything in particular that made you look for a day service/ start at the centre

Can you recall what was the main reason for you to come here to the centre?

How did you find out about the service?

Did anybody recommend the service?

How do you get to the centre? How is that organised? Does that work ok? Is there anything that causes problems?

Can you remember when you first visited the centre. How did that go?

Are there any activities you enjoy when you are at the centre? What sort of things do you like to do at the centre?

Is there anything in particular you like about coming to the centre? Why?

Can you tell me about anything that you think works well whilst at the centre?

Can you tell me anything that hasn't worked so well, or anything that could be improved?

Just to reassure you, the centre isn't closing but if the centre wasn't here could you describe what impact that would have on you?

What would you do if you didn't have the centre to go to?

Is there anything else you would like to tell me about coming here/going to the centre that you think would be useful for me to know. Is there anything else you would like to tell me before we stop?

### **Questions Staff / volunteers**

Could you start by telling me a little / give an overview about the service here?

What is the main aim/ philosophy of what you do here?

In terms of people coming to you, starting with you, could you tal about what information you have when they arrive or how you go about getting information about their needs?

Are there any strategies you use for new people when they first start attending?

In terms of the size of the group, how do you deal with the needs, likes/dislikes of the group?

In terms of the medical conditions or disability that people may have, can you talk about how you accommodate that? Any challenges? Barriers? Issues?

Could you talk a little about any links you have with other groups / agencies – what for? Works well? Not so well? Gaps?

What involvement do you have with carers?

Could you talk a little about the activities you run and why particular ones?

If you had a blank canvass in terms of what you wanted to do here, is there anything that you would like to do that you're unable to do at the moment? Why?



Is there anything else you would like to tell me about the centre that you think would be useful for me to know. Is there anything else you would like to tell me before we stop?

**Questions – Carers**

So could you start by telling me a little bit about why you started looking for a centre for xx? What did you hope it would help with?

How did you find out about the centre? What made you / did you choose that one? Did you get any help from anybody in terms of finding a centre? Did anyone suggest the centre?

Could you talk through the process of once you knew about the centre how you went about starting there? How did you access? What needs to happen in order for your relative to get there?

Would you say there had been any impact on your xx since attending the centre?

Could you talk about the impact on you since your XX started attending the centre?

In terms of their conditions/diagnosis/any illness are they managed whilst at the centre? Could you talk about their needs whilst at the centre?

In terms of your involvement with the centre, do you attend the centre?

The centre is not expected to close, if the service was no longer available could you talk a little about what that would mean for you/ your relative?

Is there anything that has not worked so well? Anything you think that could be improved on? Anything that you think could be changed or altered?

Is there anything you think would be useful for me know, anything that we've not touched on?